Effective Strategies for Improving Employment Outcomes for People with Chronic Kidney Disease

27th Institute on
Rehabilitation Issues

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Introduction

This country has many more people with vocationally limiting disabilities than Vocational Rehabilitation (VR) programs can effectively serve! When 75% of those with significant disabilities are unemployed, what then do VR programs look for in selecting and promoting client referral sources?

The answer is virtually the same for all VR programs. Resources are scarce, so agencies want referral sources that yield clients that are significantly disabled with wants and needs consistent with the VR mission of placing people with disabilities in competitive employment. It is all the better for the VR agency if these potential clients have positive, rehabilitation-affirming support systems working on their behalf.

If that's what the VR agency wants, then what does the VR counselor want in a referral? VR counselors want referrals of available, motivated people who want to work and have well developed support systems in place. VR counselors want their referrals to be stable medically and emotionally and they want other service providers involved early and often.

What if there was a referral population available to VR agencies nationwide that met all these requirements? Even better, what if this referral source was largely an untapped resource for VR programs?

Well, there is such a referral population — people with chronic kidney disease (CKD). More than 300,000 people with CKD live in the United States and incredibly few of them receive VR services. These potential clients can be easily accessed through dialysis and transplant facilities in every state. Another potential referral source is the nephrologist's office.

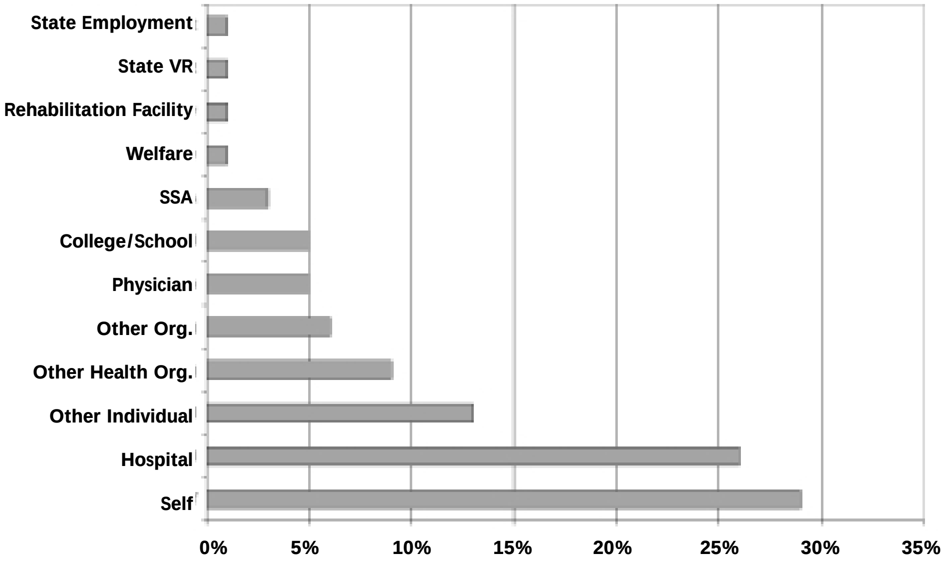
The vast majority of these potential referrals receive SSI and/or SSDI benefits because Social Security considers anyone with kidney failure to have a presumptive disability qualification. Additionally, even people with kidney failure who have not yet qualified for SSI or SSDI benefits still qualify for Medicare, making this the only disability group that does so. Therefore, they would pose little or no medical expense to VR.

Someone with CKD has a built-in support system in his or her medical treatment team. This team can offer tremendous support of rehabilitation efforts and includes a social worker as the principal contact for the VR counselor. A social worker can speed up and enhance the provision of VR services by providing medical information and reinforcement for VR service delivery and follow-up. In other words, the social worker can be a true partner.

The all-important support system for someone with CKD includes not only the healthcare team and family but also advocacy groups such as the American Association of Kidney Patients (AAKP), the End-Stage Renal Disease Networks (Networks), the Life Options Rehabilitation Program, National Kidney Foundation (NKF), and the Renal Physicians Association (RPA). These groups are genuinely committed to rehabilitation for people with CKD, and they have developed effective strategies and abundant educational materials — all to promote rehabilitation. Read more about these organizations in the Directory of Resources and see examples of programs in the Toolkit, some of which are national and others could serve as model programs.

Of the 368,662 clients served and closed by VR in FY 1999, 1,249 (0.3%) were diagnosed with kidney failure, the last stage of CKD. Of the clients with kidney failure served by VR and closed, 45% were closed with an employment outcome. These clients with kidney failure came from a variety of referral sources.

Who Referred Successfully Rehabilitated People with Kidney Failure FY 1995



Source of Data: Rehabilitation Services Administration

So, with all that people with CKD have going for them, why aren't they more popular with VR? Over the years many myths have proliferated about those with CKD. Unfortunately, believing these myths has kept the rehabilitation and renal communities apart. These myths are so strongly held that people with CKD have accepted them as fact.

Myths range from “dialysis clients are too sick and unstable to work and will die soon” to “they are expensive cases” to “dialysis interferes with a normal work schedule or even VR counseling appointments” or “people with CKD who are working or have had a transplant don’t need and aren’t eligible for VR services.” The term used in the federal legislation that entitles people to Medicare based on kidney failure — End Stage Renal Disease — helps to proliferate the myth that anyone who has kidney failure will die soon. Although without treatment kidney failure is terminal, people on dialysis or successful transplants are still living after more than 30 years.

The facts are that people with CKD generally cost less to rehabilitate and return to work at a higher pay rate than other significantly disabled populations served by VR. Advances in treatment and a genuine emphasis in quality of care on the part of the renal community are generating employment-ready referrals in large numbers. A growing number are willing and able to work. People with CKD who worked before dialysis or transplant and later receive VR services are much more likely to remain employed after dialysis and/or a transplant.

Vocational Rehabilitation Closures FY 1999

Successful Rehabs	ESRD	Other Major Disabilities
Weekly earnings at application	$14.57	$39.73
Weekly earnings at closure	$269.53	$251.93
Average cost to rehab	$2,358.02	$2,989.80

Source of Data: Rehabilitation Services Administration

There you have it. You’ve made a new discovery. You’ve learned the truth. If you’re ready, all you need now are the “how to’s,” and this publication will be your guide.

So why wait?

Chapter One

What is Kidney Disease and Its Treatment?

Chapter One

What is Kidney Disease and Its Treatment?

What are the functions of the kidneys?

The kidneys have many functions. They:

- Adjust the body’s fluids
- Balance the body’s blood chemistry and electrolytes
- Remove waste products from the body
- Release several hormones

What are some of the symptoms of chronic kidney disease (CKD)?

Different people have different symptoms and different abilities to cope with them. Usually the first sign of CKD is a general feeling of tiredness. Other major warning signs may include:

- A change in the frequency or pattern of urination
- Burning during urination
- Bloody or coffee-colored urine
- Swelling of the face, feet or abdomen
- Lower back pain
- High blood pressure

Are there other symptoms of CKD?

Yes, other symptoms of CKD are:

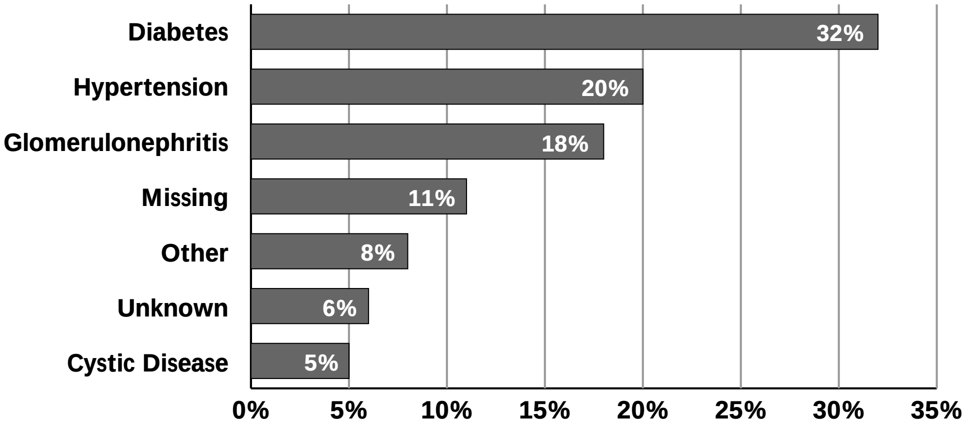
- Inability to concentrate
- Dizziness
- Changes in sleep patterns
- Restless legs
- Generalized itching
- Decreased appetite, nausea, vomiting

- A metallic taste in the mouth
- Weight loss
- Numbness in arms and legs
- Feeling of coldness
- Burning sensation in the feet
- Headache

What are common causes of kidney failure?

Chronic kidney failure occurs from the destruction of normal kidney tissues over a long time. In the US, the most common cause of kidney disease is diabetes, which is especially common among those who are African-American, Hispanic, Asian, or Native American. People with diabetes and kidney failure often have other complications related to diabetes, including retinopathy and neuropathy. Hypertension is the second most common cause of kidney failure in the general population, but is the leading cause for those who are African-American. Other causes of chronic kidney failure include glomerulonephritis, recurrent urinary tract infections, polycystic kidney disease, kidney stones, and many others. *Acute kidney failure* may result from trauma, surgical complications, severe bleeding, and toxicity due to medications. Fortunately, most people will recover from acute kidney failure, whereas, those with chronic kidney failure will inevitably require some type of dialysis therapy or kidney transplantation.

Causes of Kidney Failure 1998



Source of Data: USRDS 2000 Annual Report

Is it possible for someone to have CKD and not know it?

CKD may be present for several years without causing any obvious symptoms or problems. However, when kidney function falls below 25-30% of normal, a variety of symptoms may develop, as described above. The presence of CKD might be suspected by a history of past medical problems, a family history of kidney problems, by physical examination, and/or lab results.

Are there stages of CKD?

In simple terms, stages of kidney disease progress from being at increased risk of developing kidney disease, to increasing levels of kidney damage, to kidney failure. The precise stage of CKD is determined by measuring someone's kidney function through laboratory assessment and his or her symptoms.

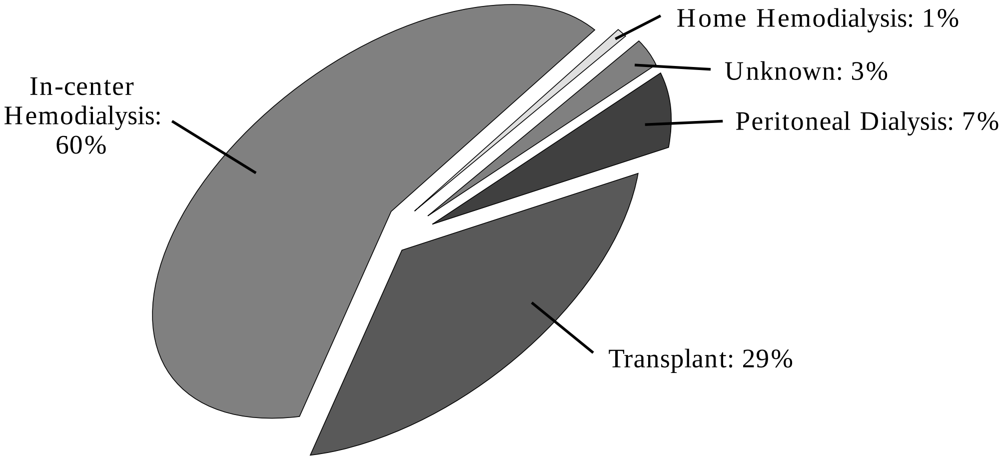
What is the treatment for CKD?

As kidney function decreases, special attention must be paid to controlling blood pressure, avoiding medications that can worsen kidney disease, and for diabetics, strict blood glucose control. Occasionally, dietary modifications may be advised. Recently, it has become evident that the use of certain medications, such as ACE inhibitors (angiotensin-converting enzyme) or ARBs (angiotensin receptor blockers) may slow the rate of progression of kidney failure. Treatment of the underlying kidney disease may require the use of other medications, such as corticosteroids (cortisone) or immunosuppressives.

Since many people with kidney disease also have other comorbid medical conditions, additional considerations often include treatment for elevated blood cholesterol levels and other risk factors for arteriosclerosis. In fact, in addition to its role in causing vascular disease, cigarette smoking is an independent risk factor for chronic kidney failure. Medications may be used to control blood phosphorous and calcium levels to prevent serious bone disease, which is a major complication of long-standing kidney failure. Most people with kidney failure develop anemia because the damaged kidneys cannot produce a hormone that normally stimulates the bone marrow to make red blood cells. Erythropoietin (EPO) may be administered when people with chronic kidney disease develop anemia. It usually results in improved stamina, energy, ability to work, and performance of other activities of daily living. Importantly, correction of anemia may be very helpful in preventing the development of an enlarged heart and congestive heart failure.

Past efforts to control the progression of kidney failure were of limited value. Newer strategies are extremely promising, however, and it is likely that many people can be expected to live long and productive lives despite having kidney disease, with or without dialysis and transplantation.

Treatments for Kidney Failure in 1998



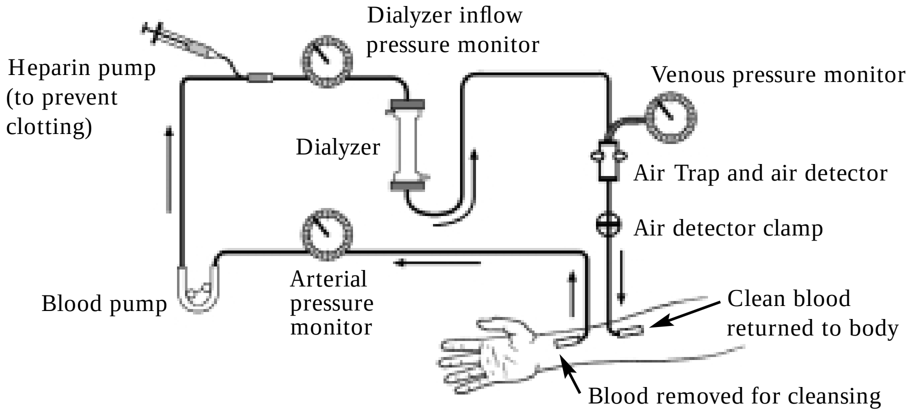
Source of Data: USRDS 2000 Annual Report

What is *dialysis*?

Dialysis is a way to clean the blood by “artificial means”. Dialysis does not make the kidneys work better. In other words, dialysis is a treatment that does the work that damaged kidneys cannot perform. Dialysis removes from the blood wastes and extra fluid that build up because of kidney failure. There are two types of dialysis – hemodialysis and peritoneal dialysis. Hemodialysis can be performed in an outpatient facility, or patients can be taught to perform their treatments at home. Peritoneal dialysis is generally performed in the home. Currently, two methods of peritoneal dialysis provide excellent options for patients who choose this form of treatment: continuous ambulatory peritoneal dialysis (CAPD) or continuous cycling peritoneal dialysis (CCPD), or a combination of both methods.

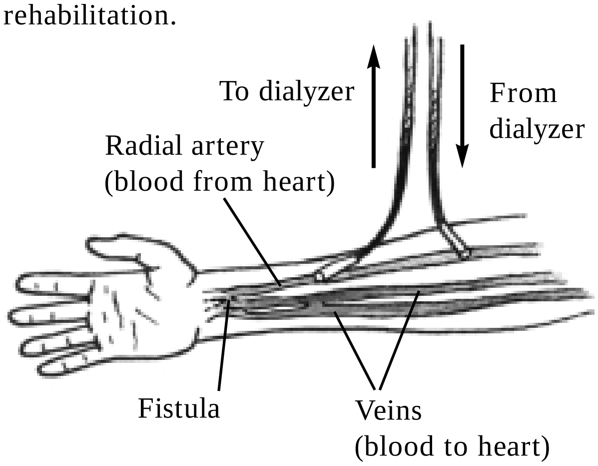
What is hemodialysis?

“Hemo” means blood and “dialysis” means being put through a filter. Hemodialysis uses an artificial kidney machine (dialysis machine) to remove fluids and waste products from the bloodstream. In order to perform hemodialysis, some type of vascular access must be created. Creating an access requires surgery to connect together an artery and vein in the arm (called a "fistula") or to insert an artificial blood vessel (called a "graft') either in the arm or in the thigh.



Hemodialysis

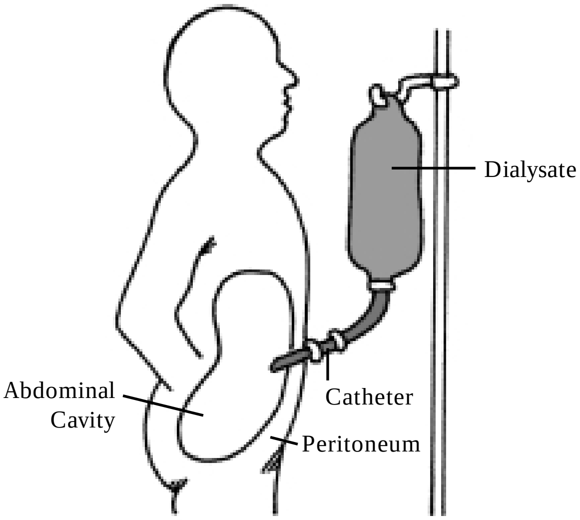
Occasionally, it may be necessary to use a temporary or permanent external catheter. Blood circulates from the vascular access through the artificial kidney, and then is returned to the patient in a continuous process that usually lasts from 3 to 4 hours. Hemodialysis treatments are usually performed three times weekly (Monday, Wednesday, and Friday, or Tuesday; Thursday, and Saturday). One of the most important factors leading to a successful and healthy life on dialysis is having a properly functioning vascular access. Many patients are diagnosed with kidney failure late in the course of their illness. This makes it difficult to have the time for the best access to be placed, heal, and develop correctly. It takes several months for a fistula to satisfactorily mature. Consequently, many patients have to use dialysis catheters or may undergo numerous access procedures, leading to increased hospitalization and other obstacles for rehabilitation.



Arteriovenous Fistula

What is peritoneal dialysis?

Instead of using an artificial kidney as in hemodialysis, in peritoneal dialysis, the abdominal cavity is used as a filter. A specially designed dialysis catheter is surgically inserted through the abdominal wall, often just below the umbilicus (belly button). The dialysis solution that contains glucose and various minerals, called dialysate, drains through the catheter into the abdominal cavity (called the peritoneal cavity). During the time this solution remains inside the peritoneal cavity (dwells), waste products, excess fluid, and salt are drawn out of the body tissues into the solution. At the end of the dwell time, the dialysate is then drained and discarded. The patient drains a fresh bag of dialysate into the peritoneal cavity through the peritoneal catheter, and the process is repeated.



CAPD and IPD

People who use CAPD may do 4-6 “exchanges” a day, with the dialysate solution remaining inside the peritoneal cavity for 4-6 hours. Dialysis supplies simply include bags of dialysate (usually 2-3 liters), the plastic tubing that attaches to the bag, and a warmer (a heating pad or microwave oven). The bag and tubing look like an IV bag and tubing. The entire exchange procedure takes only about 20-30 minutes, making this form of dialysis particularly appealing for many people.

CCPD uses a machine called a cycler to heat the dialysate, drain it in, track the time the dialysate dwells in the peritoneal cavity, drains the dialysate out, and measure the amount of fluid removed. Most patients do CCPD while they sleep, but occasionally they may need to do an extra CAPD exchange during the day to get enough dialysis.

Most peritoneal dialysis patients tolerate the extra fluid extremely well, with little change in their appearance or ability to perform necessary physical tasks. Many are able to work or attend school full-time and adapt their dialysis exchange procedures to what their lifestyle permits or requires.

What will help people on dialysis feel their best?

Obviously, the best measure of how well people are doing on dialysis is how well they feel and how satisfied they are with their quality of life. Assessing this requires understanding all the factors that affect someone's health, including treatments and multiple constantly changing social and economic issues.

Ideally, doctors will manage their patients according to clinical practice guidelines and performance measures developed by professional organizations. The Renal Physicians Association (RPA) has established clinical practice guidelines on initiation and withdrawal of dialysis and how to prepare a patient for dialysis and transplantation. The National Kidney Foundation (NKF) has clinical practice guidelines that address stages of CKD and recommended interventions, effectiveness of hemodialysis and peritoneal dialysis (dialysis adequacy), anemia management, vascular access, nutrition, bone disease, and blood pressure control. These guidelines offer tools for physicians and other dialysis staff to use in adjusting dialysis prescriptions and medications to optimal levels.

What is transplantation?

Many people view transplant as a cure but it is merely another form of treatment for kidney failure. Kidney transplantation is an excellent option for many with kidney failure. Despite newer drugs and other treatments to reduce the incidence and severity of transplant rejection, some patients must still rely on dialysis in order to stay alive. Immunosuppressive drugs may cause kidney failure and other potentially serious side effects. They must be taken indefinitely and they are very expensive. This last point is extremely important because hundreds of patients return to dialysis each year because they are cannot afford to pay for their medications. Federal legislation has been enacted to cover the cost of immunosuppressive drugs for transplant patients who are Medicare beneficiaries with certain limitations, but this law does not help many others who have inadequate or no insurance drug benefits.

Kidneys used for transplantation are obtained from living (related or unrelated) or deceased organ donors. Until recently, approximately 75 % of kidney transplants have came from cadaveric donors — those who signed organ donor cards stating that they wanted to have their kidneys and other organs used in the event of their death or whose families made this decision on their behalf. In the past, only the transplant recipient's parents, children, or siblings could serve as live donors. Advances in immunosuppressive medications have opened the door for transplanting kidneys from genetically unrelated people, usually a spouse, more distant relative, and even a close friend. Some people have even donated kidneys to total strangers.

Can anyone get a kidney transplant?

Everyone is entitled to be evaluated for transplant. Total contraindications to transplantation include active malignancy or infection, and certain other medical conditions. Psychosocial stability is an important criterion for transplantation because nonadherence with medications greatly increases the risk that the transplanted kidney will reject. Having adequate insurance coverage for the transplant surgery, post-transplant care, and immunosuppressive drug is another important consideration. Unfortunately, many otherwise excellent transplant candidates choose not to pursue transplantation for financial reasons.

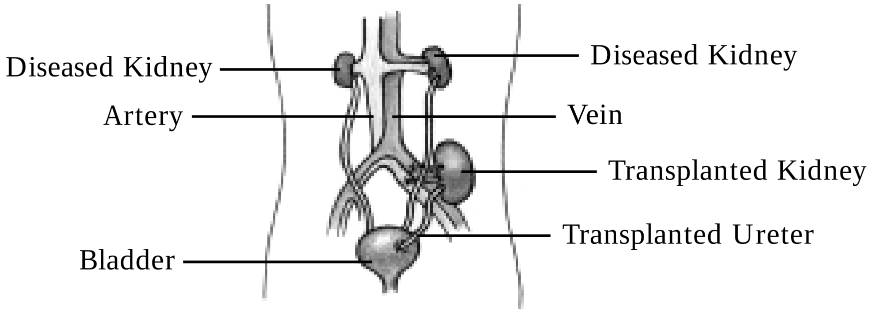
An extensive medical and psychosocial evaluation is performed prior to determining whether someone is suitable for transplantation. In many circumstances, additional surgery must be performed to correct serious conditions, such as coronary or peripheral vascular disease. Each transplant center develops its own guidelines for suitability, pre-transplant testing, and post-transplant treatment protocols. The United Network for Organ Sharing (UNOS) has a wealth of information about transplantation.

1998	**Number**
Number transplants performed	13,212
Number waiting for transplant	38,232
Average wait for 1st cadaver kidney (days)	956
Average wait for 1st live donor kidney (days)	451

Source of Data: 2000 USRDS Annual Report

Where is the transplanted kidney placed?

The transplanted kidney is placed in the pelvic area, just beneath the abdominal muscles. It rests between the pelvic bone and the colon where it is well protected.



Are there complications after transplant?

Yes, our bodies resist the presence of a foreign substance or tissues from an outside source the same as our bodies fight bacteria and viruses that cause illness. Many people who receive kidney transplants experience some degree of rejection. Having a rejection episode does not mean that kidney will stop working permanently. Special medications can be given to anyone who experiences a rejection episode. After transplant, the recipient is taught how to spot early signs of a rejection episode and when to notify the transplant team.

How long does it take to recover after transplant surgery?

The recovery period varies with each patient and depends on many variables, such as how well someone tolerates anti-rejection medications, whether there are surgical or post-surgical complications, and how quickly the transplanted kidney functions. Usually, someone with a kidney transplant can return to “normal health and activities” within three months after transplant.

Will someone appear any different after a transplant?

Immunosuppressive drugs frequently have side effects, including changes in skin and hair. Cortisone-like drugs may cause the transplant recipient to gain weight and have a round and puffy face. Acne and increased facial hair may also be a problem, but these untoward effects often improve with reduction in dose. Weight gain can be prevented by maintaining a healthy diet and by exercising regularly. Other immunosuppressive drugs may cause gum tissue overgrowth, skin cancers, and other problems. These conditions are easily treated, but require regular attention.

What medications might someone with CKD take and do they have any side effects?

People on dialysis take an average of 8 different prescribed medications daily,[1] although some may take more and others less. People on dialysis usually take multivitamins, calcium and vitamin D supplements to prevent and control bone disease, anti-hypertensive medications, iron supplements or intravenous iron, erythropoietin injections, and many require stool softeners or laxatives. Those with diabetes usually take insulin or oral hypoglycemic agents. Other medications include those for pain, gastrointestinal problems, mood disorders, and anticoagulants. Many people experience medication side effects; dialysis and transplant patients may be at greater risk because of the increased number of medications they are required to take.

What innovations in the treatment of kidney disease enhance the employment potential of people with CKD?

There have been several. Some of these include:

- Erythropoietin (EPO) is a hormone that prevents anemia by helping those with kidney failure to make red blood cells. Regular monitoring and treatment of anemia with EPO and oral or IV iron allow those with kidney failure to consistently feel stronger and have better endurance. More patients with kidney disease can work full or part-time and even perform more physically demanding tasks than prior to 1990. Before EPO was made available, people with kidney disease had to receive blood transfusions to treat anemia. Multiple transfusions led to increased risks for development of hepatitis and antibodies making it more difficult to get a transplant. Since EPO, doctors need to transfuse those with kidney disease much less, reducing the risk of serious blood borne diseases that could require hospitalization or spells of disability.
- The focus on outcome management prevalent in the renal industry today has led to development of practice guidelines to improve the quality of care, quality of life and potential for people with kidney disease to work, attend school, volunteer, and pursue age appropriate

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[1] United States Renal Data System, USRDS 1998 Annual Data Report. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases. Bethesda, MD, April 1998. www.usrds.org

activities. In addition to the K/DOQI Guidelines, adequate nutrition (often referred to as albumin management), exercise, quality of life, dialysis adequacy, anemia management, and improvements in vascular access, have reduced hospital admissions and prolonged life. New transplant anti-rejection medication have improved success rates for both cadaveric and living donor transplants. Transplantation offers the best chance of full-time employment because treatment demands are generally lower and health may be more stable. Technology may make it easier for people to get kidneys from non-compatible donors, from cloning, or even from animals.

- Nightly and daily home hemodialysis offer increasingly stable blood values reducing the need for some medications and improving functioning and well-being. Patients using this form of therapy have experienced excellent results with improved stamina, decreased dietary restrictions, decreased requirements for blood pressure and other medications, and improved quality of life. Doing dialysis at night while sleeping or for a couple of hours daily would interfere with work less and allow more patients to work full-time jobs. These therapies are being evaluated for cost effectiveness in several centers in the US which could result in increased Medicare reimbursement and widespread usage.

Who is available in the clinic to assist patients?

Each dialysis facility is required to have a health care team to assist people with kidney failure. The health care team includes a nephrologist, licensed professional nurses, technicians, dietitians, and masters level social workers. It is important for anyone with kidney disease to be an active participant on this treatment team.

What can VR counselors do to learn more about the person and the disability?

VR counselors report that visiting a dialysis or transplant facility helps them better understand about kidney disease and treatment. Such interaction also offers an opportunity to meet key professionals with whom they can collaborate to improve vocational outcomes for their client. Dialysis and transplant facilities can be great locations to recruit new clients. A VR counselor who sets one of the early appointments with a new client during his or her dialysis, may even be able to request a care conference with the client and staff, get paperwork signed, and pick up essential medical records. For more information, see *Where Do I Go For More Help* or the *Directory of Resources* sections of this document.

Living With CKD: A Client's Perspective (Case Study)

I've known most of my life I had kidney disease. From the first physicals I got in junior high, they knew something was wrong. It wasn't until I was in college that kidney disease was diagnosed. When it was diagnosed, the treatments were expensive and not covered by insurance, so the nephrologist said simply, "This is something you will die from some day. Exactly when we can't say." This is not what teenagers like to hear!

My kidneys continued to fail gradually over the years. My mood was driven by my lab tests. If my creatinine levels were stable, I was in a great mood. If they dropped, I would be depressed for days. The thing that got to me was the inexorable nature of it all. I knew my kidneys were failing, I knew there was little I could do about it, and I knew I would hit a dead end eventually.

A couple years ago, it got to the point I had to get ready to go on dialysis. I went to a dialysis center to see what it was like. I watched someone sit in a chair and have this machine suck out his blood, clean it, and put it back. I had a panic attack and had to leave. I just couldn't see myself being able to sit in a chair like that for 3 hours, 3 times each week.

I was in denial to the point that I had to have emergency surgery to put in a temporary catheter and go on hemo. As soon as I could, I went on peritoneal dialysis. It meant more surgeries, but I felt I had more control over my life. It was still pretty grim. I had to watch what I ate, how much water I drank, how much I traveled, and what kinds of activities I did. It just got more and more depressing.

When I was called about a transplant, my first reaction was fear. Even if I hated dialysis, I knew I would live through it. The transplant surgery scared me. I almost said no over the phone. When we got to the hospital, I still kept telling myself I could walk out if I wanted. As they wheeled me into surgery, I saw a small cooler sitting in the hallway. That was too much, I was getting up the nerve to tell them I changed my mind when they knocked me out. That was the best thing to happen.

I woke up feeling better than I had in years. The medication helped, but I just felt better. Over the next year, I kept feeling healthier until I couldn't remember ever feeling less well than I did. The medication and threat of rejection are always there, but for me, transplant was the way to go.

As I look back now, I see how the chronic kidney disease really shaped my life. I chose careers because of my interest in medicine and rehabilitation. I chose and rejected jobs because of the insurance. I chose not to have kids until I was certain the therapy was good enough so I could live to watch them grow up. Even then, I didn't want to have birth children because I didn't want to risk them inheriting what had caused my kidney disease.

If I could tell rehabilitation counselors anything, it would be that people with chronic kidney disease make great clients. It's just that, as we get sicker, we don't have enough energy to do much, so we look tired and lazy. As we listen to physicians, we get depressed and think we are in a hopeless situation. By the time we start dialysis, we are convinced we have little to offer and less to enjoy. So you have to reach us early, when we have energy, confidence, and hope.

Whatever you do, don't look at someone sitting in the dialysis chair and form your impressions on the basis of what you see. And for goodness sake, tell social workers what VR does. My social worker knew nothing about VR and acted like I may as well give up trying to make a living.

Chapter Two

Referral

Chapter Two

Referral

Can the applicant with kidney failure work?

Yes, definitely. People with kidney failure bring many assets to the world of work. Many applicants with kidney failure have at least a high school education and many have college or post-graduate degrees. Many have prior work histories. If they are working when they start dialysis, many continue to work. An understanding employer can help by adjusting the work schedule to fit with the dialysis schedule. The applicant's dialysis facility may be able to schedule hemodialysis to allow those that are working to return to work as soon as possible following initiation of treatment.

What are the most likely sources of referral for those with chronic kidney disease (CKD)?

Potential applicants with CKD are plentiful, and there is help available to access them more easily. There are three primary referral sources for adults with CKD:

- Dialysis facilities
- Transplant centers
- Nephrologists' offices

The primary referral contact in nephrologists' offices is generally the office nurse or the social worker, if the practice has one. For dialysis and transplant centers, the social worker is the primary source of contact to obtain referrals.

Referrals of adolescents can come from the school in addition to the above sources. The primary point of contact in the school is the special services coordinator, the school nurse, or teachers, the same referral sources for youth with other disabilities through transition of school to work programs.

How can VR counselors access appropriate referrals of those with kidney disease in areas with many providers?

When a large number of nephrologists' practices, dialysis facilities, and transplant programs exist, VR counselors can turn to organizations that can help link the counselor with appropriate referrals through dialysis and transplant facilities in a specific VR service coverage area. The National Kidney Foundation (NKF) has affiliates throughout the country. Affiliates maintain contact with the dialysis and transplant facilities and with nephrology social workers employed by these centers. Many social workers working in dialysis and transplant facilities are members of the NKF's Council of Nephrology Social Workers (CNSW). NKF can make introductions and provide the names of appropriate social workers. In addition, NKF affiliates can include VR in seminars and invite VR personnel to speak to groups of those with kidney disease and renal professionals.

Another organization that can help VR counselors identify potential referral sources is the End Stage Renal Disease Network. There are 18 ESRD Networks (Networks) across the U.S. that are charged with overseeing care in dialysis and transplant programs and promoting rehabilitation of those with CKD. Like NKF affiliates, Networks can link VR counselors with dialysis and transplant facility personnel and promote VR through publications and conferences for patients and staff.

Another organization that can link VR counselors to appropriate referrals is the American Association of Kidney Patients (AAKP). This national organization, made up of people with CKD, has chapters in many states and members eager to help others with kidney disease link with VR agencies.

Who is the mostly likely source of VR referrals from dialysis and transplant facilities?

The nephrology social worker is the vocational contact at both the dialysis unit and transplant center. These social workers are charged with assessing and helping those with psychosocial needs, including rehabilitation. For instance, if someone tells his or her physician about interest in returning to work or trouble on the job, the physician will most likely refer him or her to the nephrology social worker. As part of their comprehensive psychosocial assessment, nephrology social workers assess employment status within 30 days of initiation of treatment. They provide counseling, education, referral and concrete services as each need is identified. Typically, the social worker is the facility staff member who makes referrals to state VR. It is essential for the VR counselor to collaborate with and educate nephrology social workers to help them understand services and how to make appropriate referrals. A good place to start is to offer to make a presentation at a CNSW meeting. Contact the NKF affiliate to learn how to seek time on the CNSW meeting agenda. Meetings are open and VR counselors can attend to solicit referrals. The NKF affiliate can add VR counselors to the mailing list to receive meeting notices.

Where can VR counselors find the most up-to-date medical information on an applicant with CKD?

The dialysis or the transplant center has recent and accurate medical information on potential rehabilitation referrals. Medical records are constantly updated. Those who receive in-center hemodialysis are seen by a physician, physician assistant, or nurse at every treatment while those that receive home dialysis treatment or have a functioning transplant are seen less frequently. The VR counselor can contact the dialysis facility social worker who will bring the medical form to the nephrologist's attention. VR counselors who need additional information can contact nephrologists directly.

For applicants with multiple diagnoses in addition to CKD, the VR counselor will need to contact other practitioners if these diagnoses could potentially affect employment. If the applicant is also receiving psychological counseling outside the dialysis or transplant facility, it is important to contact that mental health provider too.

Who can provide information about the applicant's financial resources and insurance coverage?

Applicants are the first resource for this information. In addition to assessing the applicant's vocational status and goals, the nephrology social worker is the staff member at the dialysis and transplant facility that has the most recent information on applicants' health benefits and financial status. If more detailed information is required, the VR counselor can contact the local Medicaid office and ask to speak to the specialist on dialysis-related coverage or someone who can answer questions about this coverage. For information on Medicare coverage, there is a special handbook for dialysis and transplant services (see the Directory of Resources section). If applicants have private insurance and a benefit issue needs to be addressed, the VR counselor could contact the plan administrator or ask applicants for a copy of their benefit booklet.

How stable is the applicant's condition?

Like those with any chronic disease, applicants with CKD may have episodes of acute illness. However, once applicants with CKD adjust to dialysis or recuperate following a transplant and learn how to take care of themselves, their health should stabilize and functioning should improve. When someone starts on dialysis, it often takes a month or more of treatments to physically adjust to treatment. Some people starting dialysis continue working without a break. Others need to take a leave of absence to physically adjust to treatment.

What are the emotional and/or psychological effects of dialysis?

Emotional adjustment can take a year or longer as people grieve for the loss of their kidneys, health, and even their dreams and aspirations just as someone would grieve following the death of a loved one. The applicant's mood may range from excitement and anticipation to moodiness and seeming lack of motivation at different interviews, depending on the stage of grief the applicant is experiencing at that time. Applicants often have issues related to body image that can affect their emotional adjustment. The VR counselor should be alert to changes in mood and refer applicants to mental health professionals when appropriate.

How will the applicant who is just starting dialysis appear during an intake interview?

Applicants just starting hemodialysis may have a catheter inserted into their upper chest or chest. There may be two plugs sticking out from this catheter that are covered with a dressing. The catheter has to be kept clean and is only temporary until someone can have an access placed, usually, in the lower arm. Usually clothing will hide the catheter.

When a hemodialysis access is surgically placed under the skin, the applicant's arm may become swollen, red, and tender. Most accesses are placed below their elbow, but sometimes an access is placed above the elbow on the inside of their upper arm or even in the thigh. With time the swelling and redness should go away. However, a hemodialysis access may appear prominent and bumpy and there will be scars where each access has been placed.

A peritoneal catheter is surgically placed in the abdomen before someone starts peritoneal dialysis. This takes a few weeks to heal. While the catheter site is healing, an applicant may feel discomfort and some pain. The VR counselor may observe these applicants having difficulty sitting down, standing up, or bending since these movements can aggravate where abdominal muscles were cut.

Unless an applicant has a rounder belly because of extra fluid, it is difficult to tell he or she is on peritoneal dialysis because clothing hides the catheter.

Do applicants with kidney failure need to make any lifestyle changes?

In addition to having dialysis or a transplant, applicants with kidney disease need to understand and follow their diet and medication prescription. Learning to live with treatment for kidney failure may be a minor adjustment for some people or it may demand a major change in lifestyle and choices for other. As stated previously, most of those with kidney failure experience some depression, sadness, and/or anxiety about what kidney failure will mean to their lives as they adapt.

How important is it that applicants follow diet and fluid prescription?

It is extremely important that applicants on dialysis or applicants with a kidney transplant understand and follow their prescribed diet[2] and fluid restriction (if any) to avoid complications of kidney disease. Some complications of CKD include bone disease, congestive heart failure, and even heart attack. Applicants on dialysis must usually restrict their intake of potassium, phosphorus, sodium, and fluid and eat more protein to avoid malnutrition. Dialysis and transplant facilities have renal dietitians who educate those with kidney failure about their diet and fluid prescriptions and provide regular laboratory updates to help them see how well they are adhering to their dietary and medication prescription.

Common reasons for non-adherence include lack of understanding, depression, denial, and finances. Applicants should be encouraged to talk with their doctor, dietitian, nurse, or social worker about diet and fluid restrictions and seek tips to help them adhere more closely. The social worker may be able to help them locate financial resources if this is a barrier to adherence.

Where does the applicant with kidney failure do dialysis?

To learn more about each of the treatment options, read Chapter 1. In brief, in addition to transplantation, dialysis options for CKD include:

- Hemodialysis if done in a dialysis facility requires little training
- Hemodialysis if done at home requires about 6 weeks of training

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[2] National Kidney Foundation: Clinical Practice Guidelines for Nutrition in Chronic Renal Failure, 2000. www.kidney.org/professionals/doqi/doqi/doqi_nut.html

- CAPD done at home requires 1-2 weeks of training
- CCPD (cycler) done at home requires 1-2 weeks of training
- A combination of CCPD done at night and one or more CAPD exchanges during the day requires 1-2 weeks training

What is the applicant's dialysis schedule and how long do treatments last?

As shown in the chart in the Introduction to this document, the most common type of dialysis by far is in-center hemodialysis. Applicants on in-center hemodialysis have treatments three times a week on the same schedule every Monday, Wednesday, and Friday or Tuesday, Thursday, and Saturday. Some centers offer early morning or evening shifts. Schedules vary for Thanksgiving, Christmas, and sometimes for New Year's. The next most common type of dialysis is continuous ambulatory peritoneal dialysis (CAPD). With CAPD, applicants must do exchanges 4-5 times daily 7 days a week. A CAPD exchange takes approximately 30-40 minutes and is generally done around breakfast, lunch, dinner, and bedtime. Someone who does continuous cycling peritoneal dialysis (CCPD) also called automated peritoneal dialysis or cycler dialysis uses a machine to do dialysis exchanges overnight during sleep. Those on home hemodialysis do dialysis three times weekly just like in-center hemodialysis. Short daily home dialysis is done two hours a day usually before or after work and nocturnal daily home hemodialysis is done overnight during sleep. These latter two daily types of dialysis are being evaluated for cost effectiveness and are only available in a few dialysis facilities. Any form of home dialysis is less likely to interfere with the applicant's vocational evaluation, training, work or school schedule than in-center hemodialysis.

How flexible can the dialysis schedule be?

Applicants that need dialysis receive it on the same schedule each treatment. However, applicants can request a different dialysis time for short periods or permanently. Facilities can prioritize schedules for those who are working or in school. Some dialysis facilities have dialysis shifts that start early or continue after 5 p.m. Those that do not offer evening dialysis state that low utilization, higher labor costs, and concerns about safety in some areas are reasons for not doing so. If enough people request it, a facility that does not offer an evening shift may consider offering one.

If an evening shift is not available and work hours cannot be changed, an applicant may need to consider changing to a facility that can accommodate his or her work schedule. Dialysis Facility Compare (see Directory of Resources) has information on facilities offering dialysis after 5 p.m. and those that offer home dialysis. The Network can also provide this information.

How might the applicant with chronic kidney failure feel before and after dialysis?

This depends on the applicant and the type of dialysis. Because treatment is gentler and more like normal kidneys function, applicants on peritoneal dialysis (CAPD or CCPD) do not generally feel much different before and after dialysis. Some applicants on hemodialysis feel the same before and after dialysis while others feel sluggish and fluid overloaded before dialysis and/or “washed out” and exhausted after dialysis. Some symptoms can be avoided if applicants with kidney disease are careful about the amount of fluid they drink and what they eat between dialysis treatments. Adherence is essential to optimize health and ability to work or attend school or training.

How might kidney disease affect the applicant’s stamina?

When kidneys fail, the body may not be able to make a hormone called erythropoietin. In healthy people, this hormone alerts the body when more red blood cells are needed to carry oxygen to all the tissues of the body. Applicants who have too few red blood cells are anemic. Anemia causes symptoms of fatigue, low endurance, lack of energy, memory problems, and can lead to cardiac complications. Anemia becomes more pronounced with dialysis and usually improves with kidney transplant. Applicants should be encouraged to know their laboratory counts, to report symptoms, to take oral or intravenous iron and intravenous or subcutaneous injections of erythropoietin (EPO), to get adequate dialysis, and to exercise. All help keep anemia under control.

How does the applicant think working might affect his/her health?

Some applicants with kidney failure may worry about how working will affect their health. Those who have not worked for some time while they were ill may be more likely to have this concern. Applicants who worked while on dialysis are less likely to be concerned about how working will affect their health. Suggest that applicants talk with their nephrologist or other healthcare provider about what they can do to stay as healthy as possible. In most cases, working appears to help those with kidney disease do better physically, emotionally, and financially.

How does being on dialysis (or having a transplant) affect an applicant's ability to work?

There is likely to be some variability in different applicants' ability to work. For those on dialysis, fatigue may keep them from returning to former employment, especially if their physician restricts certain kinds of work. How the applicant feels immediately before and after dialysis and the time needed for dialysis can limit type of work and work hours. These issues can be addressed by looking at job restructuring or accommodations that allow the applicant to keep their current job or to obtain new employment.

By contrast, applicants with successful kidney transplants do not have scheduling restrictions and may be able to handle jobs requiring more physical labor. Applicants with functioning transplants may be restricted from working in direct sunlight, with chemicals, or at healthcare facilities where they might be frequently exposed to infectious diseases because of side effects of immunosuppressive medications they take to keep the body from rejecting the transplant.

Does the applicant have any sensory limitations?

Applicants on dialysis are more likely to have neuropathy if they have diabetes or if the dialysis provided is not enough to remove toxins effectively and applicants with diabetes can also have vision loss and/or mobility impairments. In some cases, antibiotics given for infections may have affected hearing and caused dizziness.

What kinds of working conditions might the applicant need to avoid?

Applicants with anemia feel changes in temperature more than healthy people. They often complain of being cold even when others are comfortable. Therefore being outdoors in cold temperatures may not be advisable. Some need to remain in air conditioning during the summer. Others like to spend some time outdoors so they can rid themselves of extra fluid and toxins by perspiring. Applicants on CAPD need a clean environment during the brief time that they perform a dialysis exchange.

Applicants with new kidney transplants should avoid crowded places in the initial few months following kidney transplant because the immunosuppressive medications they take make them more susceptible to germs. Those who do not perspire normally should avoid working outdoors in hot temperatures to avoid heat stroke. Applicants with successful kidney transplants do not have to avoid dusty environments, but they should avoid environmental hazards, including chemicals, that could damage their transplanted kidney. The nephrologist or transplant surgeon could provide information on what workplace hazards potentially damage kidneys.

Might the dialysis access sites pose any work limitations?

Applicants on dialysis must protect their dialysis access from prolonged weight that could cut off the blood flow through it. These applicants should also avoid allowing sharp objects anywhere near their access site without wearing protective covering. Because accesses are placed under the skin, the only risk of infection in the workplace would be if the access is punctured. In this case, applicants should put enough pressure on the puncture site with a bandage to stop the bleeding and seal the wound. As soon as possible, applicants should then notify their treatment center.

Some applicants on dialysis are embarrassed about how their dialysis access looks. Multiple needle sticks leave scars in different areas of the hemodialysis access. Some of those on hemodialysis worry that those who have never known someone on dialysis will think that they use recreational drugs. For this reason, they may wear long sleeves year round.

In most cases, hemodialysis catheters in the chest or neck area are under clothing. Applicants should avoid any activity that could potentially puncture or dislodge the catheter and should keep the exit site clean and dry. Applicants should be encouraged to ask a dialysis nurse what kind of dressing to use if the workplace is wet or especially dusty.

Peritoneal catheters are sewn into the abdominal tissues and hidden and protected under clothing. Applicants should avoid work activities that might poke through clothing and puncture the catheter as this could cause leaking and peritonitis, an infection.

What kind of limitations in lifting, bending, reaching, prolonged standing, walking, stooping, or kneeling might applicants on dialysis have?

Because applicants on dialysis often have lower strength and endurance due to anemia and lack of physical activity as their kidneys were failing, they may need both a physical functioning assessment and exercises to strengthen their muscles. Exercise and anemia management are important to give these applicants the greatest opportunity to be fully functional, including being employed.

Some doctors restrict the amount of weight that an applicant on hemodialysis should lift in order to protect the vascular access. Others believe that no amount of weight lifted will damage the hemodialysis access. There is no known scientific evidence that links lifting specific amounts of weight to an increased risk for hemodialysis access problems. Since with CAPD two or more liters of fluid are carried in the abdominal area, these applicants should ask their physician and/or home training nurse how much weight they can lift without risking getting a hernia.

Applicants on dialysis may need to rest intermittently on the job to gather strength to continue physical activity, especially if the job is a physical one. Those who get dizzy when moving from one position to another (orthostatic hypotension) should allow time to adjust to a new position.

Is a kidney transplant a possibility for this applicant?

A kidney transplant offers enhanced opportunities for rehabilitation, but it is not a cure. Some applicants may not be interested in receiving a kidney transplant because of such concerns as fear of surgery, success rates, and financing transplant. Others may not be candidates because of their physical condition and high surgical risks. Applicants who are not likely to be candidates for transplant include those with HIV infection, metastatic or untreated cancer, severe psychiatric illness, psychosocial problems that cannot be resolved, and coronary artery disease that cannot be corrected. Applicants with substance abuse history, chronic liver or cardiac disease, genito-urinary abnormalities or chronic urinary tract infections, or poor lower extremity circulation will need further testing before being considered for a transplant. Applicants whose cancer is in remission must postpone transplant long enough to be sure that cancer cells do not linger in the body. Those with a substance abuse history must have completed treatment. Transplant facilities have policies about how soon they will list someone for a kidney transplant after a cancer diagnosis or after substance abuse has ended. The United Network for Organ Sharing (UNOS) has a wealth of information about transplantation (see Directory of Resources section). Finally, someone who is not a good candidate for a transplant may still be an excellent candidate for vocational rehabilitation.

Is the applicant on a transplant list and does he/she have a pager?

In 2001, there were almost 48,000 people awaiting kidney transplant. In 1999, about 12,500 kidney transplant were performed, of which less than 4,500 were from live donors.[3] Because there are few living donors, most applicants that need a kidney will wait for one from someone who has died and donated their organs.

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[3] U.S. Facts About Transplantation, United Network for Organ Sharing. Retrieved February 20, 2001 from the World Wide Web: www.unos.org/Frame_default.asp?Category=Newsdata

Contrary to what many people believe, the transplant list is not on a "first-come, first-serve" basis and it takes time to be evaluated and listed. Under the current system of organ allocation, time on the transplant waiting list varies greatly. How long someone will wait depends on his or her blood group (A,B,O, or AB), tissue type (HLA match), antibody (PRA) level, time on the waiting list, and age (for children). Those needing multiple organs (such as a kidney-pancreas transplant for a diabetic with kidney failure) generally wait less time. There are national policies on how organs are distributed. Each transplant program has its own criteria for who they will transplant.

Applicants who are told they are not candidates at one transplant program can interview at a different program. Some applicants may choose to be listed at more one transplant program — perhaps one locally and another in an area where waiting times are shorter. Applicants who have been evaluated by the transplant team and determined to be good candidates physically and emotionally often get beepers to notify them if a potential organ is available so they can contact the transplant program quickly no matter where they are. UNOS recommends that potential transplant recipients live no more than six hours from any transplant program where they are listed.

Does the applicant anticipate being hospitalized for a transplant soon?

Only applicants with willing and eligible live donors can answer this question affirmatively. Transplant programs evaluate potential live donors including parents, siblings, and even non-related people such as spouses, friends, or occasionally unselfish strangers. Other considerations besides health status include age, antigens, and blood group. A transplant from a live donor can be scheduled at the convenience of both the donor and recipient. Once employed or in school or training, the applicant should also consider job or school demands since getting a transplant will require time off for recuperation.

Most transplant recipients spend a few days in the hospital although stays may be longer if complications arise. Recipients generally recuperate at home for the next 4-6 weeks. Often they can return to work in three months, sooner if they have a job in an "isolated" office setting. When it is safe to return to work is not generally based on the surgery itself, but is based on the risk of infection until immunosuppressive medications are regulated to a safe level.

A kidney transplant is considered major surgery. An applicant who has an unsuccessful transplant can return to dialysis and eventually get back on the transplant list. Some people with kidney failure have had multiple kidney transplants during the course of kidney disease.

Might applicants with kidney transplants have any limitations?

A donor kidney is placed in the lower abdomen and in most cases natural kidneys are not removed to get a kidney transplant. As stated previously, it takes time to heal, for the kidney to stabilize in its new body, and to regulate the immunosuppressive medications. There are no specific work limitations for kidney transplant recipients except that a high SPF sunscreen is essential if applicants are considering outdoor work to reduce skin cancer risk. Those applicants with transplants who have brittle bones from having been on dialysis for a number of years may need to limit some types of work. The transplant surgeon or nephrologist is the best source of information for specific physical limitations that could affect employment of an applicant with a transplant.

How often does the applicant have medical appointments?

Those who do hemodialysis at a center must go for treatment three times weekly on a set schedule. They need to stay for the entire prescribed treatment time each treatment and cannot skip a treatment or they risk illness, hospitalization, and death. They also have doctor's appointments occasionally. Those who do home dialysis have clinic appointments about once a month, but they may need to go to the clinic more often for EPO injections, blood draws, or if problems arise.

Transplant recipients have appointments very frequently immediately following a transplant. The time between these visits lengthens to monthly during the first year. If there are complications, such as rejection episodes, doctor appointments may be more frequent for awhile. As the time since the transplant gets longer, appointments are farther apart and eventually an applicant with a transplant will go to his or her doctor annually or if problems arise. Applicants should be encouraged to keep all appointments, even if they feel healthy. It is especially important for applicants with transplants to get medical attention when they feel ill as this could be an early sign of rejection that could be resolved with medication.

How important to a successful vocational outcome is a support system for applicants with kidney failure?

Many people with kidney disease start out with a pessimistic outlook and a negative impression concerning life with dialysis. This is a significant barrier to a successful employment outcome. Applicants and their families must believe that employment is possible. Renal professionals can inform applicants when technological advances occur that could improve functioning. They can also inform applicants and family members about what applicants can do to improve their chances for successful vocational rehabilitation.

Family and friends can provide critical support that strengthens applicants' ability to cope with changes they confront as they undergo treatment and as they attempt vocational rehabilitation. This support network can help applicants address the uncertainty of changing health, treatment, and stress of attending school or training and looking for a job. It can help ensure that applicants stick to their dialysis schedule, seek transplant evaluation, and follow through on planned activities, including VR appointments. An extended support network can also include local support groups for applicants with kidney disease and their family members. Some NKF affiliates and dialysis and transplant programs have peer support programs for people with kidney disease and their families. Online support groups can also provide the encouragement applicants need to actively pursue vocational rehabilitation. (See Directory of Resources section for more information).

Research has shown that family members and members of the healthcare team, especially doctors, strongly influence perceptions of those on dialysis regarding their ability to work (Curtin, 1996). It is important to find out if applicants or their families are concerned about loss of cash or medical benefits and whether they believe that working or attending school will compromise their health. If so, the applicant and/or family could consciously or unconsciously sabotage a rehabilitation plan. The treatment team can clear up misperceptions. Family members may experience grief and loss associated with role changes and need emotional support (see Directory of Resources for caregiver support).

Dialysis and transplant personnel may discourage applicants with kidney failure from working if they believe working will lead to loss of Medicaid or other health insurance. It may be important for VR counselors to educate dialysis and transplant personnel about work incentive programs that allow applicants to keep these benefits and/or the availability of jobs with benefits in the area.

The Dialysis Social Worker As A Referral Resource (Case Study)

He began hemodialysis in 1998 when he was 41. Before starting dialysis, he worked for warehouses and did construction work. Immediately after he began hemodialysis, as the dialysis social worker I completed my psychosocial assessment, talked with him about his work experience, and suggested he seek VR assistance from the Texas Rehabilitation Commission. Instead, he declined and applied for Social Security Disability.

I continued to talk with him, educating him about his options including the availability of work incentive programs. I encouraged him to set long and short-term goals and reminded him that VR services were available to him. During his second year on dialysis, he felt better physically and decided to apply for VR services.

I referred him to the VR office that served his area. I made sure that his medical records were transferred to the VR counselor in a timely fashion and with his consent, I communicated with the VR counselor about his special needs as someone on dialysis.

After reviewing his medical records and assessing his vocational interests and goals, the TRC counselor and the client decided that he should seek further training. The TRC counselor helped him to locate financial assistance and a program for computer technician training. While on dialysis, he completed his coursework and certification exam and was seeking employment when he received a call recently for a cadaveric transplant.

While he is recuperating from surgery, his VR case has been suspended. He is keeping in close contact with his VR counselor and is anxious to begin his new career with her help when his health stabilizes.

Chapter Three

Vocational Service, Planning, and Delivery

Chapter Three

Vocational Service, Planning, and Delivery

What are the client's vocational goals?

Clients with kidney disease have the same types of vocational goals as other job seekers and they may do many different types of jobs. People with kidney disease have been automotive engineers, business managers, computer software developers, computer system analysts, counselors of various types, data entry personnel, daycare providers, food service workers, investment counselors, janitors, nurses, occupational therapists, physicians, police officers, postal workers, rehab counselors, teachers, telemarketers, woodworkers, etc. Self-employment and telecommuting occupations are attractive alternatives for clients with CKD. The list of possibilities is endless.

If the client is working now, what might he need from VR to help him/her keep the current job?

For those who are currently working, the key to keeping them on the job is to develop a plan with the client, the employer, and the treatment team to address issues that might threaten continued employment. For those on dialysis, there might be scheduling issues, hospitalizations, and changes in physical abilities. For those on the transplant list, there would need to be time off for the actual transplant, adjustment to medications, and any complications that might arise. For transplant recipients, there would need to be time off for laboratory tests and doctor's appointments. A proactive plan which leaves the lines of communication open, maximizes the likelihood that the client will be able to keep his or her job and the assistance of a VR counselor can make the difference.

Is the client looking for immediate work or a career?

This depends on the client. Some clients are looking for a way to supplement their income without jeopardizing their benefits. Others are tired of a life that revolves solely around dialysis and are looking to focus on a career. Clients who have received a transplant and have had some of their restrictions lifted may start to consider a career that would include benefits to help pay for their immunosuppressant medications.

Does the client want to work full or part-time?

To clients considering returning to work after a long period of unemployment and adjustment to dialysis and/or transplant, a part time job can be appealing. It allows them to test their strength and stamina. Clients who continued to work throughout their transition to dialysis or transplant may want to continue to work in that same capacity.

Is full-time work an option?

Full time work is always an option. It will depend primarily on the client's health, the employer's readiness, and dialysis unit's willingness to make the necessary accommodations that will allow the client to meet his/her medical and employment obligations.

What work hours are best for the client — before or after dialysis?

Since many studies report that those on dialysis have physical functioning below that of the general population, clients with kidney disease must establish vocational goals that match their physical strength and endurance. Many clients have other illnesses such as diabetes, hypertension, lupus, AIDS, or even mental illness in conjunction with chronic kidney disease (CKD). These illnesses must be carefully controlled through medication.

Kidney disease, dialysis, and transplantation affect people differently. What one experiences may be quite different from another. When kidneys are failing and can no longer manufacture the hormone erythropoietin, this leaves most feeling tired and weak. Some clients report that they have low blood pressure, feel lightheaded and exhausted immediately after dialysis, and cannot fully function until they have something to eat and take a short nap. For others, strength and endurance is best immediately after dialysis and for the remaining 12-18 hours. Some clients with kidney disease say that they feel best on non-dialysis days. Others feel lethargic and unable to do all the activities they want to do right before their next dialysis.

Adherence to the kidney diet, keeping lab values in the acceptable range, and being sure to get enough dialysis must be considered in establishing the vocational goal and work schedule. This calls for keeping lines of communication open among the dialysis staff, client, and vocational counselor. The flexibility of the dialysis center and the employer in scheduling work hours and treatment have an impact upon the client's morale and his or her ability to perform duties of the job, as well as the client's ability to complete every dialysis session and get enough dialysis to stay healthy.

Is it possible to schedule dialysis around work or does a job need to have a flexible work schedule for a client who is on dialysis?

How flexible work hours must be depends on whether the dialysis facility prioritizes shifts for those who work and whether it offers evening hours for dialysis. If not, perhaps the client could consider different work shifts from normal daytime hours or should schedule dialysis very early in the morning or as late in the afternoon as possible and make up work hours missed on non-dialysis days.

Would work adjustment training be an option if the client has not worked in a long time, never worked, or has a sporadic work history?

The client may need work adjustment training. Work adjustment training helps clients acquire personal habits, attitudes, and skills to function effectively on a job, develop or increase work tolerance prior to engaging in vocational training or employment, develop work habits and orientation to the world of work, gain skills or techniques to compensate for losses due to disability, and acquire job-seeking skills and locate employment. Those who are deaf, hard-of-hearing, or blind, will need specific accommodations and/or assistance to coordinate services during work adjustment.

How much money does the client with kidney failure want or need to earn?

For some, the amount of money earned may be of little or no consequence. Satisfaction from working is what they are seeking. For those receiving SSI or SSDI benefits, it is important that they earn enough from work to offset what they will lose in disability benefits and from paying taxes and other work-related expenses. If possible, any potential job should offer health benefits. If this is not possible, the salary should be either sufficient to cover out-of-pocket expenses for medical care and Medigap (Medicare supplement plan) premiums or low enough for the client to qualify for Medicaid. Clients who are receiving various subsidies will need to calculate in the costs of returning to work what they will lose in other benefits such as housing subsidies, food stamps, child care and other benefits they receive. Clients need to understand how working will affect all benefits so they can make informed decisions about the level of employment they need and want.

How do clients with CKD pay for treatment?

Kidney failure is the only disability-specific criteria that make people eligible for Medicare. About 93% of all those that need dialysis or a transplant are eligible for Medicare. Medicare is effective immediately for those who choose to do home or self-care dialysis. Medicare can start up to 2 months before a transplant if transplant is the first treatment for kidney failure. There is a 3 month waiting period for Medicare for those that do in-center hemodialysis.

If Medicare is the primary payer, after an annual deductible is met, Medicare will pay 80% of the allowable charge for outpatient care, including dialysis. After the inpatient deductible is met, Medicare pays most of the charge for inpatient hospitalizations unless they are lengthy. Medicare coverage is also available for a few medications including anti-rejection medications following transplant, erythropoietin, IV iron, and vitamin D.

Those clients that are insured through their own or a spouse's current employer health plan can apply for Medicare but it will only pay secondary benefits after the employer group health insurance pays for the first 30 months of Medicare eligibility. If the client has Medicare and the employer health insurance denies coverage for any Medicare covered services, Medicare can pay primary benefits. Medicare may pay employer health plan deductibles or coinsurance with certain limitations. See the handbook on dialysis and transplant coverage under Medicare listed in the Directory of Resources section.

Does the client need to have company health insurance and sick leave?

It is best if VR counselors look for jobs with company health insurance and sick leave for clients who have kidney disease. Even though Medicare coverage continues as long as the client with CKD pays the premium and is on dialysis and for at least three years post-transplant, it does not pay for the following things:

- Deductibles for inpatient and outpatient care
- Co pays of 20% of the allowable charge for outpatient care, anti-rejection medication and specific daily amounts for long hospital stays
- Take home medications
- Non-covered services

What other sources of help are available for a client's medical costs if the job does not offer health insurance?

Medigap insurance pays deductibles and coinsurance not paid by Medicare for Medicare covered services. Some states do not have any insurers that offer Medigap coverage to people with pre-existing conditions like kidney failure. Other states have regulations that forbid companies that sell Medigap or Medicare supplement insurance to those 65 and older from excluding those under 65 with pre-existing conditions from purchasing Medigap coverage. If their employer does not offer health insurance, clients with kidney disease need to consider obtaining or retaining Medicaid coverage.

The *Health Insurance Portability and Accountability Act* (HIPAA) credits those with recent qualifying health insurance coverage for any part of a pre-existing waiting period they met while insured by their previous health insurance when they get new health insurance.

Some states offer special coverage for people with kidney disease under state kidney programs. Eligibility and coverage varies from state to state. Contact the nephrology social worker to find out if there is a state kidney program.

Medicaid, some commercial insurance, some Medigap plans, and some state kidney programs pay for medications. Some pharmaceutical companies provide help for clients that need certain medications. Contact the social worker or see the Directory of Resources section for medication assistance.

Will a client's Social Security disability benefits be affected if he or she receives help from VR?

VR services do not affect Social Security disability benefits. However, paid work activity may affect a client's benefits, depending on how much is earned. It is important for VR counselors to understand the complex Social Security work incentive programs and continuously review them with clients who receive SSI or SSDI as they progress through their program. Clients need to understand and accept that their earnings may affect their benefits. The VR counselor can address most concerns, but specific issues should be addressed with the local Social Security office, work incentive liaison, or in some communities with the SSA employment support representative who has received intensive training on work incentives.

Transplant recipients may be especially motivated to work with VR. Their continuing disability status is automatically reviewed following transplant and they may lose benefits.

How might work incentives benefit clients with kidney failure?

The *Ticket to Work and Work Incentives Improvement Act* (TTWWIIA) makes it easier for clients with kidney disease to enter the workforce by expanding available employment service providers. In 2001, 13 states began implementing new Ticket to Work vouchers that disability recipients can use to obtain VR services from public or private agencies. By 2004 residents of all states will receive these vouchers. Since most people with kidney failure are eligible for and receive disability benefits, they should receive vouchers when their states implement the voucher system.

TTWWIIA expands Medicare for a total of 8.5 years for those who return to work who wouldn't normally be able to keep Medicare. This could be especially important for transplant recipients that have other disabilities besides kidney disease and want to work.

The TTWWIIA also allows states to expand Medicaid benefits to those with disabilities who work either without premiums or at a below market premium. Therefore, clients with kidney failure who feared losing Medicaid if they worked may be more motivated to seek job training and/or employment once they understand the new work incentives available under TTWWIIA. States that have expanded Medicaid benefits for working people with disabilities are listed on the Medicaid website.

In addition to TTWWIIA, SSA has a number of work incentive programs for recipients of SSI and/or SSDI, including those with kidney failure. In 2001, clients who receive SSDI have a nine-month trial work period (TWP). Any month that an SSDI client earns $530 or more counts as a month of trial work. In 2001, after the TWP is exhausted, SSDI clients can earn up to the substantial gainful activity (SGA) level of $740 per month ($1,240 for your SSDI clients who are legally blind) and still keep their full SSDI check. SSDI clients can earn more if they have received SSA approval for impairment related work expenses (IRWE) or blind work expenses (BWE). For the first time, the earnings limits for the TWP and SGA are now linked to the national wage index and will be increasing each year.

For SSI recipients, SSA does not count the first $20 per month or the first $65 of earned income per month in determining how much of the benefit check to reduce by earnings. Under Section 1619(a) SSA also disregards one-half of all additional earnings. SSA does not count food stamps, items donated by non-profit organizations, and most home energy assistance. SSA also does not count medical expenses someone needs to be able to work, including maintenance medications and a home dialysis assistant. For those who are blind, SSA does not count expenses that they need to allow them to work and deducts from earnings as blind work expenses income taxes paid, meals during work hours, costs of transportation, and expenses for a guide dog. VR clients that have SSI can keep Medicaid benefits under Section 1619(b) if they earn more than the state's Medicaid guidelines even if they no longer receive SSI cash benefits. The most recent 1619(b) state Medicaid limits can be found at www.ssa.gov/work/ResourcesToolkit/Health/1619b.html. SSA can provide current information on the 1619(b) earnings limit for Medicaid. A map that shows states that have implemented flexible standards for Medicaid eligibility can be found at www.hcfa.gov/medicaid/twwiia/statemap.htm.

Disabled students under 22 can now earn up to $1,290 per month or $5,200 per year without jeopardizing their SSI cash benefits. This should make it easier for young people to work part-time or temporary jobs to help pay educational expenses. These amounts are linked to the national wage index and will be increasing each year.

If clients with kidney disease have chosen in the past not to work because they believe they would have to wait for disability to start again if they have a health setback, the TWWIIA should alleviate this concern. The TTWWIIA offers expedited reinstatement ("easy back on" safety net) for disability benefits with no waiting period for those who develop health problems within 60 months after losing disability benefits. Clients can submit a one-page form to resume benefits. Benefits start right away for six months while SSA determines a client's eligibility. If SSA finds the client to be not disabled, he or she will not need to refund these provisional benefits.

Finally, transplant recipients may be especially interested in working with VR because if SSA reviews their disability status, they may be found no longer disabled if they no longer need dialysis. Under the recovery during vocational rehabilitation work incentive, SSA may continue disability benefits as long as a client is in an approved VR program, even if he or she is considered medically improved following transplantation.

If the client needs to do a CAPD exchange during work hours what kind of accommodation might he/she need?

Most clients who do CCPD do not need to do dialysis exchanges during the day. However, some must perform at least one CAPD exchange during a workday to get enough dialysis. To do a CAPD exchange, clients need a clean room and about 30-40 minutes of privacy to do the dialysis procedure. Prior to requesting this accommodation, your client will need to think about when he or she will make up the work time lost while performing the exchange.

Can applicants choose another type of dialysis if this would help them achieve their vocational goals?

Clients with kidney failure often have choices of treatment options. However, not every dialysis facility offers all modalities nor is it always medically advisable for every client to change. In addition, clients might not realize that they have a choice and may not know what clinics offer other options. It is reasonable for the VR counselor to ask how the choice of treatment was made and recommend that clients speak to their physician if changing modalities improves the chance that they can work successfully. The ESRD Network can advise the VR counselor and the client what treatments are offered by clinics in his/her area.

Can applicants choose a different time of day for dialysis if this would help them achieve their vocational goals?

Clients that are on in-center hemodialysis can ask for a different shift time. However, it may not be possible to change immediately if either the dialysis facility is full or if the preferred shift is full. The client should ask the nurse manager or administrator at the dialysis facility to write his or her request in a safe place as a reminder and the client should note who they asked and when. Sometimes someone else at the dialysis clinic will be willing to switch times but this is more likely if the switch is only temporary, such as for a vocational evaluation or a brief training. Clients often prefer their usual dialysis shift because they have gotten to know the other people on that shift and staff members. This makes some clients reluctant to change.

The VR counselor should remind applicants who are working and need to take medical leave to adjust to treatment, time off for all or part of a dialysis treatment, or to go to medical appointments that they may qualify for the *Family and Medical Leave Act* (FMLA). Under this law, they could take time off in increments as short as 15 minutes. This may help if they have to leave work early or get to work late because of dialysis or medical appointments. Of course, it is best for the employer and co-workers if the client negotiates a flextime schedule and completes job responsibilities in spite of taking time off. Although the FMLA requires notice whenever possible, it can help those who may be hospitalized without notice for access surgery, transplantation, or other illnesses. For more information on the FMLA, see the Directory of Resources section.

Can clients transfer to other dialysis facilities, such as one with an evening dialysis shift if this would help them achieve their vocational goals?

Clients that need dialysis are referred to dialysis facilities by their nephrologists. They usually have the choice of where to dialyze (unless their insurance limits this), but they may be reluctant to change facilities if it means they would have to find a new nephrologist. For those whose nephrologists are affiliated with several facilities, changing facilities is easier.

What if the client receives a transplant during delivery of services?

Depending upon the stage of the VR program that a client has reached, he or she can interrupt services for medical reasons and resume a program with clearance from the doctor and/or the medical team. For a client who is considering training, it is important to discuss with the training institution and financial aid department what the impact on training might be if there is a medical interruption. This should be done before selection of the training institution.

Can a client change his/her schedule for vocational evaluation or training program?

Whether a client with kidney disease needs a different schedule for evaluation or training depends on the flexibility of the client, the evaluation unit or training program, and the dialysis facility. Since a vocational evaluation is usually time limited, a dialysis schedule change can be avoided by arranging for the client to attend the evaluation on his or her non dialysis days. The evaluation might need to be extended to make up the missed days. In some instances, vocational evaluation is scheduled at an evaluation unit outside the client's local community. In these cases, the home dialysis facility can generally arrange transient (temporary) dialysis close to the site where the evaluation is scheduled if enough notice is provided.

For a client to participate in training programs, it might be necessary to change his/her dialysis schedule. However, depending on someone's interest, training options can be flexible. Although many dialysis facilities will change the schedule for those who work or are in school, unless someone else is willing to switch shift times with the client, unless training time is brief, this option may be best utilized when the client gets a job.

Who are the key contact people in the dialysis or transplant facility that can

address questions specific to providing optimal vocational services?

As previously mentioned, the *renal social worker* is the main contact for the VR counselor with regards to providing vocational services to people with CKD.

Contact the *physician* and/or the *physician assistant* for medical information, functional capacities, physical accommodations, and release to work. Because people with kidney disease are seen frequently, medical information VR counselors receive from the nephrologist should be recent. The social worker can often help assure that medical information is returned faster.

The *nurse manager* is also available to augment medical information provided by the physician. Additionally, she or he is usually in charge of scheduling. Contact the nurse manager if a change is needed to accommodate evaluation, training, and/or work.

The *renal dietitian* plays an important role in helping clients adhere to their renal diets. This is imperative to maintain their health and stamina. If a client reports fatigue, weakness, or poor stamina contact the dietitian to find out if dietary non-adherence could be affecting the client's ability to work.

The *dialysis technicians* probably have the most contact with clients during their dialysis treatment. If they know that a client is receiving VR services, technicians can offer support and encouragement to clients throughout the rehabilitation process.

Some dialysis facilities and transplant centers or organizations like the NKF or AAKP have *support groups* or *peer helpers*. You should encourage your clients with kidney disease to explore what is available at their facility and in their community.

The Client With CKD And Blindness (Case Study)

She is 46 years old and the first-born girl with 6 siblings. She was 9 when she was hospitalized and first diagnosed with juvenile diabetes. She recalls times when she may have done things to be hospitalized to get attention and has memories of her parents talking about how “costly” she was.

When she was 23 she experienced her first complication of diabetes — fluctuating vision. She needed laser treatments for diabetic retinopathy. By 1980 she was legally blind. Desiring independence, she moved from her family’s home into an apartment and began working as a waitress and than as a nurse’s aide. Busy, she did not manage her diabetes as she had been trained to do.

In 1983 she sought help from the Texas Commission for the Blind. The vocational teacher and I helped her identify settings on home appliances to make her home accessible, provided adaptive aids and training on a talking watch, talking alarm clock, large button telephone, and large print checking ledgers. I asked a diabetes educator to evaluate her understanding of her disease. My client learned diabetes management skills and the educator recommended a talking glucose and blood pressure monitor to help her better manage her diabetes and blood pressure.

She attended the Criss Cole Rehabilitation Center in Austin TX, where she had a low vision evaluation and learned skills she would need to become more independent in daily living and to gain competence needed to retain her successful employment. What she learned included Braille, travel skills, computer keyboarding and computer adaptive technology with speech and large print to keep her medical records and financial records, use of the audio cassette recorder, money management, telephone usage, organizational, time management, and note-taking skills. She also learned kitchen safety skills and how to use adaptive in food preparation and diabetes meal planning, housekeeping, laundry, minor mending, clothing coordination and labeling.

In 1987 she became a housewife and mother and worked part time at a clothing store and as a Mary Kay Cosmetics representative. In 1988 her kidneys failed and she began in-center hemodialysis. Dialysis was taxing and she had to depend on close friends to provide day care for her son while her husband continued working and she was at dialysis.

In 1989 she received her first transplant but it failed two years later. In addition to kidney failure and high blood pressure, she now had carpal tunnel syndrome and osteoporosis. After the transplant failed, she tried peritoneal dialysis, but complications led to her return to hemodialysis. She changed dialysis schedule to an evening shift so she could have her days free and she could sleep to recuperate from dialysis. Despite her three times a week dialysis schedule, she continued to take care of her home, do yard work, build decks, paint and sing with her husband in church, and she and her husband recorded original music.

In 1996 she sought evaluation for a kidney-pancreas transplant. While waiting, she continued her homemaking responsibilities, home schooled her son, and took on the responsibility of caring for her brother and elderly father. In September 1999, she received a successful kidney pancreas transplant. High dose prednisone for a rejection episode caused a cataract that required a couple of eye surgeries.

Today, she continues to home school her son who is in 8th grade. She is a successful homemaker and home decorator. She continues to struggle and overcome limitations that would have limited less motivated people with similar circumstances. She is fully engaging in and enjoying all aspects of life. She is happy to be alive and is successful because of her independence, motivation, strong family support, faith, and help that VR was able to provide.

The Client With CKD And English As A Second Language: A Client's Perspective (Case Study)

In a blink of an eye, my life changed when I found out in 1994, at the age of 26, that I had kidney failure. After working my shift on Thursday, I came home and fell asleep. I awoke an hour later with a fever and in increasing pain. I tried to manage the fever and pain with over-the counter medications, but by Sunday I knew I needed help. I asked my ex-husband to take me to the emergency room. I spent the next 27 days in the hospital.

The doctors ran all kinds of tests and determined that I needed dialysis. Because of my health, age, and because I was a single mother with a young daughter, the doctor recommended that I learn to do peritoneal dialysis and referred me to a local dialysis clinic.

At my new clinic I met my new doctor, the nurse who would train me, and the social worker. In addition to helping me with insurance and medications, my social worker helped me look at life in other, more positive ways. She told me that I had another opportunity in life and I should try to do my best by following the doctor's orders. She mentioned that I could go back to school and prepare for a better future. She arranged an appointment with VR.

I cannot thank my VR counselor enough for all he did for me. He asked me questions about what I liked and didn't like, what I could and couldn't do, and gave me emotional support when I needed it. He tried to get me into an information technology program at ITT, but they didn't accept me because I didn't speak English well – my native language is Spanish. My VR counselor didn't give up and continued to encourage me.

In 1995, I was evaluated for a cadaver transplant. Although I thought I'd accepted my condition, the psychological testing revealed that I was depressed and I was rejected for a transplant. The transplant team recommended that I receive counseling. Because of my daughter, I decided to follow their recommendation. After a year of counseling, I was reevaluated and accepted for transplant. My younger sister came from Puerto Rico to be evaluated as my donor and passed all the tests. The transplant was scheduled for the following February.

Throughout, I kept in touch with my VR counselor. I told him I wanted to take English as a Second Language courses. I took courses in the Fall of 1995 and decided to layoff the winter quarter when my transplant was scheduled. Before my sister had to give me her kidney, I got the call that a cadaver kidney had been found. I had worried about taking my sister's kidney so I chose to have the cadaver transplant. I had my transplant in January, 1996.

I had most of the side effects of medications – round face, hand tremors, I grew hair everywhere – and I felt like I was looking at someone else in the mirror. Although I didn't like it, I understood that I needed to adapt. I decided to take control and began to exercise to keep my weight down and removed the excess hair by waxing.

In the spring quarter, I returned to my ESL course. My VR counselor told me about the NKF of Georgia's Springboard program that brings together those on dialysis and with transplants to share experiences and gain skills needed to re-enter the world of work. The director of the program, Chuck Brown, is a transplant recipient and a special man. The program helped us recognize that we were not alone and that we could live normal lives. I graduated from Springboard and with high marks from my ESL classes.

My VR counselor recommended additional training to expand my opportunities. He again recommended me again for the information technology program at ITT and this time, I was accepted. After six months, I received a certificate of completion in computer literacy and word processing and a certificate in database management. I also received an award for outstanding attendance. ITT helped me look for jobs and prepare for interviews.

I found a job as a dispute analyst/information consultant for a large credit company. I began training at my new job and continued to receive training at ITT. The hours were long – classes at ITT from 8 a.m. to noon and work from 1:00 p.m. to 10:00 p.m. I wasn't able to keep the job because of insurance. However, I felt proud that I had the skills I needed to get and hold a good job. My ITT instructors were proud of me too and selected me as the star student in my class.

However, I knew I wanted to do something else. Being ill myself, I knew I wanted to work in a job where I could relate to other ill people. Today, with help from VR, I am studying in the School of Radiologic Technology at Grady Memorial Hospital. Over the 2 years I have been in the program, I have had excellent attendance and have maintained an A average, one of the highest in the class. I will graduate this summer as a radiologic technologist.

I have had my ups and downs because life is not easy. I have new opportunities and do not want to waste more time. I want my daughter and parents to be proud of me and I don't want people to feel sorry for me. I know in my heart and in my head that I am a strong woman. Only God and I know what I have been through and I am very happy to see how far I've come. I'm doing what I like and people see me as useful. I live day-by-day and have always said that whatever God wants that is what will be. As for my future, I just applied in the School of Ultrasound at Grady. I will find out the middle of June if I am accepted. The world is full of opportunities and with God's will everybody chooses their own road. I give thanks to God and to all the wonderful people that believed in and helped me achieve my success.

Chapter Four

Job Development, Job Placement, Job Retention

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Job Development, Job Placement, Job Retention

What medical benefits do clients on dialysis retain once they start work?

If clients are on dialysis, they keep Medicare indefinitely as long as they pay premiums, even if they work. Although Medicare coverage is secondary indefinitely for workers with other disabilities, for those with kidney failure, employer group health plans are only responsible for primary coverage during the first 30 months they are eligible for Medicare. Therefore, if a client becomes employed during the first 30 months of Medicare entitlement, the employer group health plan would only be required to pay primary for the remaining months of the coordination period. If the client becomes employed after the first 30 months of Medicare entitlement, Medicare would pay primary and the employer group health plan would pay secondary.

Even though they have indefinite Medicare coverage while on dialysis, those dialysis clients who have other disabilities and are considering a transplant need to know that the months they work on dialysis can reduce the 8.5 years of Medicare they are entitled to under the *Ticket to Work and Work Incentives Improvement Act* (TTWWIIA). If they later get a transplant and still are considered disabled, they should ask Social Security how many months of Medicare entitlement they have left.

What medical benefits do clients with a transplant retain once they start work?

Employer group health plans are required to pay primary benefits for clients with transplants for the first 30 months of Medicare entitlement. If a client with a transplant did not work for part of the coordination period, the employer group health plan would only be responsible for primary benefits for the remaining months of the 30-month coordination period.

Unless clients with transplants have other disabilities besides kidney failure, they lose Medicare coverage three years after their kidney transplant. Clients with transplants who are physically able to work and only eligible for Medicare because of kidney failure need to obtain employment with health insurance coverage during the first three years post-transplant, if possible. It may help them to know that they will be eligible for Medicare again if they need to resume dialysis or if they qualify for Medicare due to age or disability.

If transplant clients have other disabilities, under the TTWWIIA they can keep Medicare for 8.5 years from the date work starts. Medicare pays a portion of all Medicare covered inpatient and outpatient services, including anti-rejection medications as long as clients with kidney disease have Medicare.

What can a VR counselor do to help those with kidney disease who still have disability or health benefits through a former employer?

Those who are insured through former employers' disability or group health plans may risk even more if returning to work leads to termination of disability and insurance benefits. It is important to ask what health and disability benefits, if any, your clients receive from their former employers and whether there is a possibility that they could return to any position with the former employer. VR counselors can help these clients by referring them to potential employers whose salaries are sufficient to offset disability benefits and whose health benefits cover most of the costs of medical care.

How much does a client need to disclose about chronic kidney disease (CKD) to a potential or current employer or supervisor?

Clients with kidney disease need to understand that they do not need to disclose the nature of their disability. The timing of when they disclose facts about their kidney condition is up to them. Failure to disclose a disability at hiring does not preclude their right to ask for reasonable accommodation later.

The *Americans with Disabilities Act* (ADA) (see Directory of Resources) permits a prospective employer to ask if any reasonable accommodations are necessary to perform the job for which the client is interviewed, but not to ask the nature of the disability. If a potential employer requires all applicants for a position to have drug testing, a client on dialysis may need to offer a blood sample for testing instead of a urine sample.

All potential employees must be able to perform the essential functions of the job, including those with kidney disease. If dialysis or transplant clients believe they can do the essential job functions but need an accommodation to do so, they should request the accommodation as soon as they know they need it. Clients and employers can negotiate reasonable accommodations.

Some accommodations that have been granted include:

- Flextime for dialysis or to keep medical appointments
- Privacy to perform peritoneal dialysis exchanges
- More frequent breaks to conserve energy

In considering hiring someone who has a disability, the employer's major concerns are getting the tasks done, maintaining the morale of staff, and not having to spend a lot of money on accommodations. VR counselors know how to address employers' concerns and uphold clients' confidentiality and privacy rights. It may help an employer to know that in general those on dialysis do not miss more work than other employees,[4] they may not need accommodation at all, and if they do, accommodations they need are generally inexpensive. Clients who have kidney disease are first and foremost prospective employees, not merely people with a chronic disease.

How can the VR counselor encourage job retention for people with CKD?

As stated in Chapter 3, the VR counselor can be invaluable in developing a proactive plan that enhances communication between the client, employer, VR counselor, and healthcare providers. For employed clients with kidney disease, the key to keeping them on the job is to develop a plan with the client, the employer, and the treatment team to address issues that might threaten the job situation. For those on dialysis, there might be scheduling issues, hospitalizations and changes in physical abilities. For clients pursuing transplant, there would need to be time off for the actual transplant, adjustment to any medications and complications that might arise. For those with a functioning transplant, there will be need for occasional clinic appointments.

If someone's work abilities change and he or she can no longer perform the essential functions of the job, the VR counselor can assist the client and the employer in determining if a different position within the company can be identified or what accommodation might be needed. If a job change is required, the VR counselor can assist in the transition and possibly augment any additional training that might be required.

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[4] Friedman N, Rogers TF: Dialysis and the world of work. *Contemp Dial and Nephrol* 9(1):16,18-19, 1988.

Who can provide detailed information regarding whether a position is within the client's functional abilities?

The nephrologist and the dialysis unit are key partners that can provide information related to your client's ability to begin training or work. The physician can provide the client medical clearance. The VR counselor needs to work closely with the dialysis facility or transplant center in the development of the physical and scheduling accommodations needed by this population.

What kinds of jobs should a client with CKD avoid?

Clients with CKD can do any kind of work for which they have the skills. Kidney disease per se does not limit career choices. As long as clients with kidney disease have health insurance or sufficient salary to pay medical expenses and are able to have some reasonable accommodations for their therapy, they are not limited in their career choices.

What kinds of environmental conditions should someone with CKD avoid?

Clients on hemodialysis who have either fistulas or grafts in their arms or thighs have small scabs or scars where needles have been inserted for hemodialysis. Some clients on hemodialysis may have closed catheters placed in their chest or neck temporarily while the dialysis fistula or graft in their arm or thigh heals. Clients on peritoneal dialysis have a closed catheter that is permanently placed in their abdomen and hidden under their clothes.

It is important that dialysis clients avoid working in any conditions where bacteria might compromise the hemodialysis or peritoneal dialysis access site. However people on dialysis can farm or garden and work with many chemicals. People on dialysis may be more susceptible to illness because they have poor immune system response. Some doctors recommend avoiding environments where they might be exposed to illnesses. However, most doctors place few restrictions on people on dialysis because they believe these clients should maintain normal routine if possible. If dialysis or transplant clients have hepatitis B or C or AIDS, they could be restricted from certain jobs as would any other VR clients with these diseases.

Clients with kidney transplants take immunosuppressant medications to lessen the chance of rejection. These medications further reduce their body's ability to fight off infection. Therefore, they should avoid jobs that present a high risk for infection soon after receiving the transplant. Later, as the dosage of these medications is reduced, the risk of infection subsides and their doctor may lift some restrictions. A client with a transplant should avoid exposure to those chemicals that could be nephrotoxic (harmful to the kidney) to protect their transplanted kidney.

Can someone with CKD work a 40-hour week?

Many clients may find it difficult to work a 40-hour week as kidney disease gets progressively worse before treatment is needed. Although this varies, as kidney function deteriorates, they may feel tired and generally run down. After they adjust to their dialysis treatment or recover from a transplant, they will be more likely to be able to work a 40-hour week. Clients who do hemodialysis at a dialysis center will need to schedule hemodialysis around work, which may be difficult because of the time involved unless the dialysis facility offers flexible or evening scheduling. Home hemodialysis or peritoneal dialysis will present few or no barriers. After a transplant, there should be no barriers to working a 40-hour week.

Can someone with CKD work an 8-hour day?

After clients with kidney disease begin and adjust to treatment, many can work an 8-hour day. If clients on in-center hemodialysis are concerned about working 8-hour days with dialysis, they should arrange their dialysis and work schedule so they can do their full dialysis treatment before or after work or work 8-hour days on the days they do not receive dialysis. Some dialysis facilities offer evening dialysis and many jobs offer flex-time or shifts when dialysis facilities are closed. For those clients that do home hemodialysis, peritoneal dialysis, or those who have kidney transplants, there should be no barriers to working an 8-hour day.

Can someone with CKD work overtime?

People on hemodialysis or peritoneal dialysis can work overtime if it is scheduled in advance. In-center hemodialysis is less flexible than home hemodialysis or peritoneal dialysis although each form of dialysis requires getting a certain amount of dialysis per day or per week to assure adequate removal of toxins (wastes). It is possible for someone to work overtime as long as notice is given in time to schedule dialysis. After a transplant, there should be no barriers to working overtime.

Can people with CKD travel as a function of their job?

Local travel poses no restrictions providing the dialysis schedule is maintained. If out of town travel is required day trips generally do not require scheduling dialysis at a destination. However, for longer trips, hemodialysis can often be scheduled in or near the destination city as long as the client's health insurance pays for out-of-area dialysis. Medicare pays for dialysis anywhere in the U.S. Managed care plans may not pay for dialysis out of network so clients with managed care coverage will need to clarify their insurance coverage.

Although in-center hemodialysis usually requires 1-2 months notice or longer to plan, if there is an urgent need for travel, dialysis personnel in many areas will do their best to accommodate clients needs. If clients on hemodialysis regularly need to travel for work to specific locations, it may be possible to make standing reservations at one or more dialysis facilities. Clients on peritoneal dialysis can carry supplies for a day or two in a car or on an airplane. Those on CCPD can either take a portable cycler and supplies on a trip or do CAPD while out of town. For longer trips, clients on peritoneal dialysis can order supplies delivered to their destination hotel or office. Clients on dialysis who are on a transplant list must notify the transplant facility how to reach them if they will be out of town. Transplant recipients can travel with no restrictions but must remember to follow their medication regimen closely.

A number of publications and websites offer information about dialysis facilities throughout the world and travel options for people on dialysis. Some of these include "The List" that appears annually in *Dialysis and Transplantation* and websites: www.dialysisfinder.com (U.S. dialysis facilities) and www.globaldialysis.com (includes international dialysis facilities). Clients can look for specific U.S. dialysis facilities and their outcomes on Dialysis Facility Compare (see Directory of Resources). Clients who have to travel for their job need to be aware that clinical practices and conditions vary, which is especially true outside the United States.

What happens if work interferes with treatments?

For those on dialysis, treatments take priority over work because without adequate treatment, he or she will not feel well enough to be a good employee. Clients should make every effort to go to hemodialysis at their regularly scheduled time. It is difficult to reschedule and important that people on dialysis get the prescribed number of hours of dialysis per week. Work probably will not interfere with home hemodialysis or peritoneal dialysis. Home hemodialysis clients can adjust their dialysis time and/or days each week as needed. As long as your peritoneal dialysis clients have the opportunity to do the fluid exchanges, they will stay healthy. Clients on CAPD only need 20 to 40 minutes to complete a fluid exchange every 3 to 4 hours or usually only one exchange at work each day. Clients on CCPD need a continuous period of 8 to 10 hours of dialysis while they are sleeping but may need to do one CAPD exchange during the workday to get enough dialysis. Clients on home dialysis need time off from work to attend regular clinic appointments.

After a transplant, the only way treatment would interfere with work would be if the client has a rejection episode and needs to go to the doctor or be hospitalized for a few days to change medications and stop rejection. If the transplant rejects, the client may need time off to resume dialysis and physically adjust to it.

What needs to be taken into consideration when setting up a job interview?

The VR counselor needs to be aware of the client's dialysis schedule and either schedule job interviews on non-dialysis days or before or after dialysis. In addition, interviews should be scheduled when the client is typically at his or her best physically. Clients on dialysis should be able to tell you whether they generally feel better before or after dialysis.

Who can assist in identifying and implementing job accommodations?

Planning job accommodations requires a team effort. The treatment facility can identify the medical implications of the job duties; the employer can identify the available options; and the client and VR counselor can identify the best course of action. Because of the amount of time clients with CKD spend on dialysis, a common job accommodation is a scheduling accommodation. This can best be addressed in partnership with the employer and the dialysis unit. If a client needs to change his or her dialysis schedule in order to obtain and/or maintain employment, the dialysis facility social worker can be enlisted to advocate on the client's behalf. In addition, the medical director and/or unit administrator or nurse manager will also be able to assist the VR counselor in making the necessary schedule changes. For clients who need to come in late or leave work early for in-center hemodialysis, the VR counselor, the client, and the employer must address how to make up the time. Since commercial insurance pays more for dialysis during the first 30 months of Medicare entitlement, the VR counselor or client might be able to use a job that provides health insurance as a bargaining tool with dialysis facility administration when asking for a change in the client's dialysis schedule.

Clients on home dialysis will need to go to the clinic for monthly appointments and if they have a problem. Clients can either make up this time or take sick time for clinic appointments. The VR counselor, the employer, and the client on CAPD must develop a schedule that allows the client to complete a CAPD exchange and to determine when the missed time will be made up. In addition it is important to realize that the client needs a clean room and privacy for this dialysis exchange. Physical accommodations for a particular job can be accomplished in partnership with the employer. After the physician and client identify all physical limitations, the VR counselor can consult with a physical and/or occupational therapist, assistive technology specialist, and rehabilitation-engineering specialist to identify options.

How can the VR counselor enhance the dialysis client's chances of being successful in those critical first few weeks on a new job?

Notify the unit social worker and the treatment team that the client will be starting a new job. Initiate a case conference with the client and key members of treatment team to discuss job requirements and encourage optimal compliance with the client's medical regime. If clients on dialysis are successful in managing their care and continue to receive adequate dialysis, they will better be able to meet the demands of the job.

What natural helpers can VR counselors use with people with kidney disease?

The VR counselor can encourage clients with kidney failure to seek out others with kidney disease who are well adjusted and employed. With help from local dialysis and transplant facilities, the AAKP chapter, the NKF affiliate, and Network, VR counselors could establish a group for people with kidney disease. Including working people with kidney disease allows them to serve as role models and peer helpers, sources of motivation, and dispellers of fears and myths for those with kidney disease who are looking for employment. Also, if problems arise on the job, they can seek support and encouragement from other members of the group.

Can employer based training programs be an effective placement tool?

A variety of employer based training programs exist such as on the job training, work trials, work study, and internships. These programs can provide financial and counseling support to the employer while the client adjusts to work and learns the skills to perform the job. They address the physical deconditioning that may have occurred during a long period of physical inactivity. These programs can provide an opening for the VR counselor and client to educate the employer about kidney disease. They can also be used as a means to persuade employers to provide clients with kidney disease the opportunity to demonstrate that they can do the job.

Summer employment, work trials, and internships can provide valuable work experience and orientation to adolescents. They also help show adolescents and their parents that work is possible with dialysis or a transplant.

What transportation services can dialysis clients use to get to and from work?

People with CKD experience the same transportation issues as any other clients. Under Title II of the ADA, all buses and trains ordered by public transportation systems since 1990 are required to be accessible to people with disabilities. All transit systems have to provide paratransit and other special transportation for people who can't use public transportation. The ADA requires transit systems to provide a level of paratransit service that is comparable to the level of regular transit service for those with disabilities and whose transportation needs fit specific criteria. Federal law prohibits the provider from picking up a rider more than one hour before or after the requested time or charging more than twice the rate charged for fixed route service. Many metropolitan areas are far ahead in providing this service at a reduced rate or free. Application for use of the service is necessary, subscription trips can be scheduled for any purpose, and while some clients may not qualify for paratransit services, they may qualify for reduced fares for the mass transit system.

In rural areas with limited public transportation systems, getting to the job poses a major barrier to employment. Medicaid transportation, which takes clients to dialysis clinics, is not available to take clients to jobs — unless the client goes to dialysis to or from the job. Innovation in arranging transportation is required to ensure regular job attendance that will ensure job retention. Car pooling in remote areas is also feasible. Companies may provide van service for all employees if they are located far from public transportation.

Research has shown that transportation is a barrier to work for one-third of those with disabilities. Therefore, the Project ACTION Accessible Travelers Database (see Directory of Resources) was established as a cooperative effort between Easter Seals, the U.S. Department of Transportation, and the Federal Transit Administration. This database includes transportation resources for people with disabilities living in urban and rural communities. Knowing what transportation resources exist should increase opportunities for employment for people with disabilities.

Negotiating A Dialysis Accommodation (Case Study)

Mr. M. is a 45 year old male with chronic kidney disease. He was on hemodialysis for about three years, but recently switched to continuous ambulatory peritoneal dialysis (CAPD). Mr. M. felt that his strength and energy were greatly improved with CAPD and he decided to return to work.

Mr. M. was referred to State VR by his dialysis unit social worker. When he met with the VR counselor, Mr. M. expressed a desire to return to work as soon as possible. He was not interested in training. With the assistance of the VR counselor, Mr. M. found a job as a driver for a home health agency. His position required him to drive home health aides and cleaners to their positions throughout the city.

At the time he was hired, Mr. M. felt that he would be able to handle this position and do at least one CAPD exchange during work hours. His exchange usually took about 30-40 minutes. Initially Mr. M. was reluctant to tell his employer about his medical needs and he would drive home during lunch to do his exchange. This became increasingly difficult because of the long drive and time required to do the exchange. Mr. M. told the VR counselor he was afraid he might lose his position.

The VR counselor and Mr. M. met with the employer and explained Mr. M's need to do a CAPD exchange in a clean environment closer to work. The VR counselor gave the employer an informational brochure describing CAPD. The employer was forthcoming. She recommended that Mr. M. do his exchange in one of the agency's training rooms. The client, the VR counselor, and the employer accepted this as a reasonable accommodation that not only allowed Mr. M. to continue his job, but allowed his employer to keep a valued employee.

The Client With CKD And Hearing Loss: A Client's Perspective (Case Study)

I am 42 years old and have had chronic kidney disease since 1965 when I was 7 and diagnosed with kidney problems due to Alport Syndrome. There was no education for my parents or me to help us cope with kidney disease. When I was 12, my hearing started to fail. When I was 16, I developed acute kidney failure following a strep throat infection and had to start hemodialysis. I missed three days of school each week because I had to drive myself 75 miles to the nearest dialysis unit. I did schoolwork while on dialysis and on weekends and I graduated with my class without tutors or other assistance. After three months, my kidneys began to function enough for me to stay off dialysis for the next two years.

I started college, but my kidneys failed again permanently this time and I had to go back on hemodialysis. I wasn't able to finish college because of my health so I asked the Texas Rehabilitation Commission for help to go to heating and air conditioning school. My doctor gave TRC information about my health and my VR counselor evaluated me. After a couple of months I received financial help with tuition, mileage, and living expenses. I completed trade school, found a job, and started working. Unfortunately, a few months later, I found this job was too strenuous so I returned the air conditioning tools VR had bought and found a different job. I worked at a variety of jobs including working for a time as a dialysis technician.

When my family moved to Kansas, I didn't realize that VR could help me so I started college on my own but had to drop out again because of a health setback. Later, I learned I did qualify for VR help and Kansas VR helped me complete my degree in business administration. I got a job in an insurance company, but another health setback return to disability.

My family moved back in Texas. After two failed kidney transplants and two years on disability, I asked TRC to help me get a 2 year degree in computers. This time, Texas Rehabilitation Commission's evaluation was more stringent. The VR counselor wanted to be sure I was motivated and responsible. I heard her message , finished the program, and got a job with a federal agency in Kansas City.

Even though I was living in Kansas, the TRC counselor kept in regular contact with me and my employer for the next five 5 years. At her last contact she reminded me that my salary had doubled since I was first hired by the federal agency and she told me she would put this in my case record. Since I've lived in Kansas, VR has purchased two sets of hearing aids as my hearing has gotten worse. These have allowed me to further my career as a systems analyst.

If I could say anything to a VR counselor it would be people with kidney disease may have health setbacks that make them postpone a goal, but the motivated ones get back on track. I appreciated my VR counselor who had faith in me and helped me see I could be responsible and complete what I started. I would not be where I am today if it wasn't for Vocational Rehabilitation.

Chapter Five

Where Can I Go For More Help?

Chapter Five

Where Can I Go For More Help?

Where might I go to get a more general understanding of kidney disease and how it affects rehabilitation outcomes?

Educational materials on all aspects of chronic kidney disease (CKD), including rehabilitation, are available through national organizations such as the American Association of Kidney Patients (AAKP), the Life Options Rehabilitation Program, the National Kidney Foundation (NKF), and Networks. In addition, the International Center for the Disabled (ICD) has conducted research and developed training materials specifically for this population. For more information on these programs see the Directory of Resources.

Those with CKD may also have other diagnoses that will have an impact on their rehabilitation. They may have a current or past history or substance abuse which can be addressed with their substance abuse counselor or aftercare program. A large percentage of people with CKD also have diabetes and/or hypertension. Diabetes education programs and hypertension education programs are available to provide the VR counselor with relevant information.

Who can VR specialists turn to for help in providing meaningful services to people with CKD?

Resources are grouped into four major categories: dialysis and treatment facilities, governmental agencies, kidney-related organizations, and family and friends. Providing services to those with CKD requires a team approach to coordinate the delivery of highly specialized service components. There is a strong medical overlay to required services, because people with kidney disease require continuing medical care for life. A vast reservoir of resources can help both the VR counselor and those with kidney disease understand all of the issues surrounding this chronic illness and effectively building a successful rehabilitation plan. Success depends upon knowing about these resources and accessing any support these groups and organizations can offer as timely as possible.

How can family and friends help promote vocational rehabilitation for clients with CKD?

Family, close friends, extended family, and teachers can be a source of supplemental information regarding physical and emotional issues that the client is experiencing due to dialysis or transplant. They can inform the VR counselor about the client's emotional status, level of motivation, and fears. They can advocate for the client in the rehabilitation process. Once the client has started dialysis or received a transplant, support groups can be a source of information. Confidentiality must be maintained.

Family members experience grief and loss related to their loved one's kidney disease. Often caregiver support groups can be helpful. Some facilities or organizations offer caregiver support groups and there are a number of online support groups for caregivers of those with kidney disease.

How can dialysis and transplant facilities help?

Both dialysis and transplant facilities have information on innovations in medical care and equipment, pharmaceuticals, and treatment options that can enhance the client's ability to effectively participate in a rehabilitation program. Staff at the treatment facility can provide critical information concerning the appropriateness of a vocational objective. Medicare regulations[5] mandate that dialysis facilities, whenever feasible, accommodate those who are working and want to dialyze during non-work hours, consider the functional needs of those with kidney failure in care planning, and monitor progress toward the goals regularly. If those on dialysis or with transplants notify the healthcare team that treatment or side effects of medications affect their ability to work it may be possible to make changes to improve their work ability. Information about facilities is available:

- Dialysis Facility Compare (see Directory of Resources) provides information on dialysis facility locations, hours, contact information, and outcomes.
- The United Network for Organ Sharing (UNOS) website (see Directory of Resources) offers information about transplant programs, number of transplants performed, wait list times, and success rates.

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[5] 42CFR405 Subpart U, Conditions for Coverage of Suppliers of End Stage Renal Disease (ESRD) Services

Medicare regulations require dialysis and transplant facilities have the following personnel:

- *Social workers* in dialysis and transplant programs are mandated by federal regulation to have masters degrees in social work with clinical specialization from an accredited social work program. Social workers assess psychosocial adjustment to kidney failure, provide counseling for the individual and his/her family, and promote vocational goal setting, provide information about resources, and participate in multidisciplinary care planning. Social workers are usually the point of reference for referrals to VR providers and they help those on dialysis plan dialysis in other locations.
- *Medical director* and/or client's primary *nephrologist* educates the client about treatment options, prescribes treatment to promote the highest level of health, and can advocate with the nephrologist and clinic to promote schedule changes to accommodate evaluation, schooling, or work. Nephrologists' expectations have the greatest influence on whether clients work.[6]
- *Unit administrator* or *nurse manager* assigns dialysis shifts, assures that the nephrologist's treatment orders are followed, makes sure that medical records are transferred as appropriate, arranges and changes dialysis schedules, and assures that personnel are qualified, well trained, and provide quality care.
- *Dialysis nurses* and *technicians* deliver dialysis care according to the nephrologist's orders. Nurses and technicians' attitudes can help or hinder clients' vocational rehabilitation pursuits and outcomes.
- The *renal dietitian* reviews monthly laboratory results, recommends changes in diet and certain medications with the advice of the nephrologist, and helps troubleshoot dietary difficulties.

Others on dialysis or with kidney transplants who are successfully rehabilitated can serve as mentors or role models for clients to emulate.

What if the client believes his or her facility is not doing what it should for his/her health or vocational rehabilitation?

Many people with kidney disease are depressed and angry about their

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[6] Curtin RB, Oberley ET, Sacksteder P, Friedman A: Differences between employed and nonemployed dialysis patients. *Am J Kidney Dis* 27:533-540, 1996

diagnosis. Their emotions can color their perceptions of dialysis and the people caring for them. VR counselors should consider that a complaint could be based on fact or may be unfounded. Every dialysis and transplant facility must have a grievance procedure. Clients should have or be able to obtain a copy of the facility grievance policy. This should list the steps to following in addressing a complaint. As a rule of thumb, complaints should be addressed at the lowest level before they become grievances.

- The Health Care Financing Administration (HCFA) has oversight of dialysis and transplant clinics.
- The government created Networks (see Directory of Resources) to assure that people with chronic kidney failure get the best possible care. Networks have staff assigned to respond to complaints or grievances.
- Medicare also contracts with agencies, generally state health departments, to survey dialysis and transplant facilities and to respond to grievances.

What other federal and state governmental agencies can help those with CKD?

The Directory of Resources in this booklet provides a brief description of what some agencies can do to help. Some of these agencies include:

- State VR
- Social Security Administration (SSA)
- Health Care Financing Administration (HCFA)
- Equal Employment Opportunity Commission (EEOC)
- Medicare
- National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC)

Are there any programs that specifically address the vocational needs of this population?

- The National Kidney Foundation’s People Like Us, Live program educates people with kidney disease about their options for treatment, diet, and coping.
- The NKF RISE Program and NKF of Georgia’s Club Independence and Springboard help people with CKD achieve improved vocational rehabilitation opportunities and outcomes.

- Networks hold seminars for those with CKD that include rehabilitation topics and VR staff participating. Network of New York has added vocational specialist whose primary responsibility is to link those with CKD to VR services.
- State Kidney Programs
- Dialysis and transplant support organizations

Any of these organizations could provide an excellent venue for specialized rehabilitation orientation programs targeted to clients with CKD.

What federal laws protect people with disabilities, including clients with kidney failure?

Federal legislation provides protections against discrimination and supports vocational rehabilitation for those with disabilities. Laws enforced by EEOC include Title VII of the *Civil Rights Act*, *Equal Pay Act of 1963* (EPA), *Age Discrimination in Employment Act of 1967* (ADEA), Title V of the *Rehabilitation Act of 1973*, as amended, Titles I and V of the *Americans with Disabilities Act of 1990* (ADA), and the *Civil Rights Act of 1991*. Children with CKD may be protected under the *Individuals with Disabilities Education Act* (IDEA), as amended.

Some anecdotal reports of employment discrimination were received after employer group health plans became primary payers for kidney disease treatment. Reportedly employers offered incentives to clients or family members to waive health insurance benefits, terminated clients or their spouses who insured them, or did not hire clients or spouses and it was hypothesized that this could have been related to kidney disease.[7]

Those with kidney disease need to be aware of their legal rights and responsibilities. As one of the listed disabilities, clients with kidney disease are covered by the ADA as long as the employer (or staffing agency) has 15 or more employees. Minorities, including African-Americans, those of Hispanic or Asian origin, and Native Americans are at higher risk of kidney disease than Caucasians. They may be covered by the Civil Rights Act in addition to the ADA. Those over age 40 who have kidney disease are protected by the Age Discrimination in Employment Act in addition to the ADA.

The federal and state government, as large employers, employ and contract with companies that hire those with kidney failure. Government agencies have a long history of hiring people with disabilities and contract with

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[7] GAO: Medicare: Millions Saved in End-stage Renal Disease Expenditures Shifted to Employer Health Plans. GAO/HRD-93-31, December 1992.

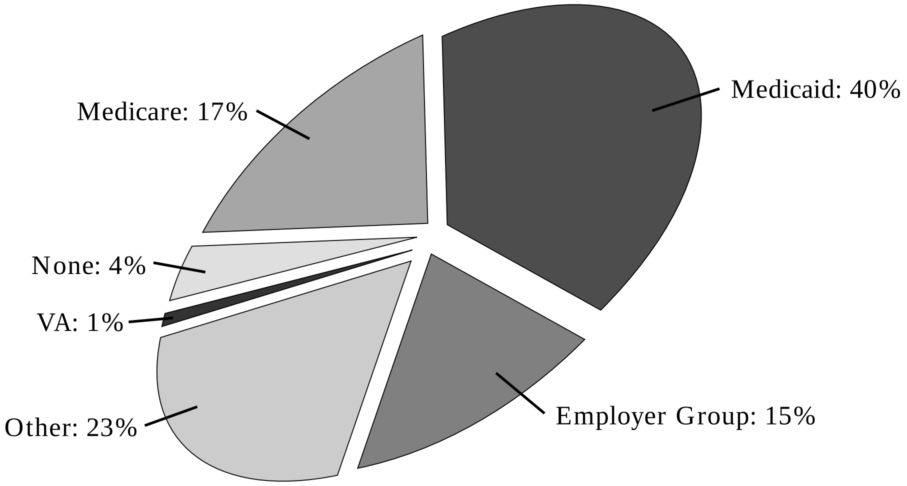
other companies who could potentially hire people with kidney disease. Government jobs offer benefits and flexible scheduling that could be attractive to people with CKD. The Rehabilitation Act covers people with disabilities in the public sector.

Clients with kidney failure requiring dialysis or transplant should be also be protected by the *Family and Medical Leave Act* (FMLA) if they and their employer meet established criteria. The FMLA allows those with serious health conditions requiring medical treatment to take intermittent or reduced leave (unpaid or paid, if accrued) to adjust to dialysis, recuperate from a transplant, or to be on time to dialysis or medical appointments. Clients should give as much notice as possible (60 days whenever possible) and attempt to schedule their time off so it will not disrupt their employers' operations. By law, employers must provide qualified employees a different position with the same pay and benefits that is more accommodating to their needs for leave. Dialysis or transplant providers should be able to provide documentation to the employer if needed.

Other laws that should help those with kidney disease include the *Ticket to Work and Work Incentives Improvement Act* and the *Workforce Investment Act*. The TTWWIIA offers a safety net for transplant recipients who need time to find employment with health benefits. This law could motivate those with dual disabilities whose immunosuppressant coverage is linked to their Medicare eligibility to work since they can keep Medicare 8.5 years. Expedited re-determination of disability may relieve the fear of those who are concerned that they could not afford to live within an income if they had to meet a new disability waiting period if they could not work due to disability in the future. The Workforce Investment Act's combining all job-related agencies into one stop centers should help those with kidney disease that lack transportation resources to obtain employment services with less difficulty.

What health coverage is available for kidney-related treatment?

Health Insurance Status of Those Initiating Treatment for Kidney Failure



Source of Data: USRDS 2000 Annual Report

About 81% of those starting treatment for kidney failure reported that they planned to apply for *Medicare*. As addressed in previous chapters, Medicare pays a portion of most inpatient and outpatient services including transplantation and all types of dialysis; however, it does not pay for take-home medications except for anti-rejection medications for transplant recipients. To be eligible someone must have enough qualifying work credits or qualify under a spouse or parent (if a child). Medicare coverage starts the first day of the third month for in-center hemodialysis. For home dialysis or transplant the 3-month waiting period is waived. A transplant recipient is eligible for Medicare the month a transplant is performed or up to two months before a live donor transplant.

There is a 30-month coordination of benefits period for those with employer group health plan coverage through their own or a spouse's current employer. During this 30-month period, their commercial insurance is primary. If they have Medicare during this period, it can pay secondary benefits. Medicare coverage continues as long as dialysis is needed, but ends 36 months after a transplant unless someone is also entitled to Medicare due to age or other disability besides kidney failure. In the unlikely event that someone on dialysis recovers enough kidney function to survive without dialysis, Medicare continues for 12 months.

Medicaid provides inpatient and outpatient coverage for eligible state residents based on federal and state policies. Medicaid can pay for medications, emergency and non-emergency medical transportation, Medicare premiums, and in some cases commercial health insurance premiums. Those on Medicaid must meet financial guidelines to qualify.

Employer Group Health Plans have different levels of coverage and may require treatment by specific providers (HMO) or encourage those on dialysis or with kidney transplants to seek treatment from preferred providers (PPO) by offering coverage incentives. Employers are not required to offer extended benefits (COBRA) benefits to anyone who has Medicare, although employers are not forbidden from doing so.

The *U.S. Department of Veterans Affairs* can help pay for dialysis for those with service connected disabilities or veterans who served during specific years. The VA will pay for medications for any veteran who has prescriptions filled at the VA hospital.

TRICARE provides healthcare coverage for active duty and retired military and their families. There are three plans including an HMO-type, PPO-type, and traditional type plan.

Other commercial payers including *Medigap* (Medicare supplement plans) plans can pay the balance on expenses that are Medicare covered. Eligibility varies from state to state. Individual health plan coverage varies according to plan and state regulation. State high risk health plans may help people pay the coinsurance amounts left after Medicare pays and may be available to provide health coverage for transplant recipients. Some plans do not accept those who have Medicare.

Some states have *state kidney programs* that provide different benefits based on eligibility guidelines. Nephrology social workers know about these programs, their eligibility guidelines, and benefits.

The State Health Insurance Assistance Program (SHIP) can answer questions general health insurance questions and questions about Medigap, Medicare, and how to file an appeal (see Directory of Resources).

Where else can I turn to find out more about kidney disease, its treatment, and employment prospects?

The Internet offers a portal to a universe of resources, which is continually updated, improved, and expanded. Colleges and universities with medical and/or rehabilitation programs are also good resources for new areas of research. Rather than provide the list of websites here, an alphabetical Directory of Resources follows.

Negotiating A Job Accommodation for A Client on Hemodialysis (Case Study)

A 42 year old male union worker who had been on dialysis for over a year returned to work after an extended medical leave of absence. He took medical leave to allow time for him to adjust to the dialysis treatment regime and regain his health following a medical crisis. When he returned to work, the dialysis unit was willing to adjust his treatment schedule to accommodate his work schedule. However, an interesting situation immediately developed with his local union!

The client worked on loading docks running a forklift and other heavy equipment. The loading dock where he worked was busy and operated two full shifts a day. Each forklift driver on the dock had seniority privileges. These privileges allowed the workers with the most seniority to “bid” the shift of their choice. Because the client had lower seniority, when the bid reached his level, no shift was available to reasonably accommodate his dialysis schedule. The nurse manager at the patient’s dialysis unit advocated for him in negotiations with the union. However the union would not budge. The client felt forced to work a shift that left him feeling exhausted and ready to quit. The nurse manager called the ESRD Network serving her area and requested assistance and guidance since no one at the clinic knew that VR could help workers keep their jobs.

ESRD Network staff contacted the local union steward and initiated a discussion regarding discrimination in the workplace. She reminded the steward that unions were formed to protect workers from unfair management practices. The ESRD Network sent the union steward and owner of the shipping company a copy of AAKP’s *Americans With Disabilities Act of 1990: Your Rights in the Workplace*. After telephone discussions, review of the material, reminders of the union philosophy of “brotherhood,” at a union meeting the patient was given the best shift to accommodate his need for dialysis.

Negotiating A Hemodialysis Shift Accommodation For Work (Case Study)

A sole breadwinner and head of a 4-member family household was working days as a manager in a lumber company while receiving dialysis in the very late afternoon/evening shift on Mondays, Wednesdays, and Fridays. His dialysis clinic was a 30-station clinic with a census of over 200 patients owned by a large national corporation and located in an urban area. This clinic was the closest one to his home and workplace. Increasing demands of his work required that he stay later on the job, causing him to arrive later for his afternoon/evening dialysis shift. He approached the nurse manager of his dialysis clinic to request a 6 p.m. to 10 p.m. shift that would allow him to continue working full time and increase his chances for promotion to the management position for which he was being considered.

The nurse manager refused his request for a later shift and stated that he could go to another clinic where they had a night shift. He explained that the additional travel time required – the other clinic was 35 miles away – would place an undue burden on his already stressful work, treatment, and family schedule. The nurse manager was further unwilling to establish a night shift because of “crime risk in the neighborhood” where the clinic was located. As a final point of argument, the nurse manager explained she would need to have least seven who wanted a night shift for her to get corporate approval, adding that there were not seven interested people. The client conducted his own survey and located seven interested patients. He contacted the ESRD Network when the situation remained at an impasse.

ESRD Network staff placed calls to the nurse manager, facility medical director (also the client’s primary care physician), and to the area manager for the dialysis corporation. She explained to all parties that most large urban facilities do offer night shifts to accommodate those who worked and that the Health Care Financing Administration (HCFA) that monitors care and pays for dialysis and transplantation is very interested in vocational rehabilitation for those with kidney failure. She pointed out that HCFA urges that facilities take all reasonable measures to help those who are working manage both work and dialysis schedules.

A compromise was reached. The client was offered a very early morning dialysis shift from 4:30 a.m. to 8:30 a.m. that allows him to arrive at work by 9:00 a.m. The unit now opens earlier and the client has to get up very early, but now everyone is relatively happy.

Advocating Coverage For Home Dialysis To Maintain Employment (Case Study)

A middle-aged nurse was working full time in an administrative capacity when she started dialysis. She wanted to continue to work full time and get her full dialysis treatments that she knew she needed to stay healthy. Because she lived in a densely populated urban setting, this created commuting difficulties during rush hour traffic. She was beginning to have problems working full time, getting 12 full hours of dialysis a week, and commuting between home, work and her dialysis facility. Something had to give. She began to explore the possibility of home hemodialysis, one of the options for treatment covered under Medicare. Medicare regulations governing dialysis and transplant facilities encourage people to select self-care modalities whenever feasible.

Her dialysis facility was supportive of her choice to do home hemodialysis with a household member/partner trained to help her with the treatment. Her professional training as a nurse made the choice seem even more logical. However, her HMO, which was her primary payer during the first 30 months of Medicare eligibility, denied payment for home hemodialysis stating that it would cost more. She found that the HMO medical director and staff had very limited knowledge of dialysis choices and believed home hemodialysis was experimental. They were not aware that Medicare promoted home dialysis nor that it reimbursed home hemodialysis at the same rate as in-center hemodialysis.

The nurse was determined and began the appeal process with her HMO. She enlisted the support of her ESRD Network and of the Life Options Rehabilitation Program, another strong advocate in the renal community. Both advocacy sources provided her with support, encouragement, and reference material as she threaded her way through the HMO appeals process. After many months, she won her appeal and today is dialyzing at home and working full time. Without her nursing background and tenacity, the outcome could have been much different.

Directory of Resources for People with Kidney Disease

Directory of Resources for People with Kidney Disease

A

ADA Building Standards: www.designlinc.com is a good place to start to research this topic.

Age Discrimination in Employment Act of 1967 (ADEA): www.eeoc.gov/laws/adea.html protects those who are 40 years of age or older.

Agency For Healthcare Research And Quality (AHRQ): provides a summary document on ESRD as a presumed disability *Determinants of Disability in People with Chronic Renal Failure* (summary Pub No. 00-E012) at www.ahrq.gov/clinic/renalsum.htm. For the full report (Pub No. 00-E013) call (800) 358-9295.

American Association Of Kidney Patients (AAKP): www.aakp.org (800) 749-2257 offers on its website educational materials as well as a list of its local chapters. AAKP is an education, support, and advocacy organization. AAKP publishes *aakpRENALIFE*, AAKP Renal Flash (electronic newsletter), *The Americans With Disabilities Act*, and other educational materials including *When Kidneys Fail*, *Hemodialysis Advisory*, *Peritoneal Dialysis Adequacy*, and *Peritoneal Dialysis… Is It the Best Choice for Me?* AAKP's Patient Plan© targets newsletters and magazines to those based on the stage of kidney disease: diagnosis to treatment (choices), access and initiation, stabilization, and ongoing treatment. Chapters offer educational programming and advocacy on returning to work.

American Kidney Fund (AKF): (www.akfinc.org) (800) 638-8299 provides education, limited financial assistance, and limited rehabilitation programming in Nebraska.

Americans with Disabilities Act of 1990 (ADA): Title 1 www.eeoc.gov/laws/ada.html prohibits employment discrimination against qualified people with disabilities in the private sector, and in state and local governments. Employers and staffing agencies that hire contingent workers also have obligations to follow the provisions of the ADA. *A Guide for People with Disabilities Seeking Employment* provides information about the Americans with Disabilities Act and can be found at www.ssa.gov/work/workta2.html.

C

Civil Rights Act of 1964: Title VII prohibits employment discrimination based on race, color, religion, sex, or national origin and provides monetary damages for intentional employment discrimination. More information can be found at www.dol.gov/dol/oasam/public/regs/statutes/2000e-16.htm.

Club Independence: www.nkfg.org (770) 452-1539 or (800) 633-2339 (Georgia) is a program for people 19 and older offered by the National Kidney Foundation of Georgia that could be used as a model in other areas (see Toolkit for a program flyer).

Combined Health Info Database (CHID): www.chid.nih.gov offers a searchable database for educational topics in different languages and formats related to various illnesses, including kidney disease.

D

Dialysis Facility Compare: www.medicare.gov/Dialysis/Home.asp provides information on facility physical location, contact information, availability of evening shift, and selected facility outcomes.

Dialysisfinder: www.dialysisfinder.com is a searchable database of dialysis facilities that requires only the name of the city and/or zip to display the facility address and contact information and print a map to any U.S. facility.

Dialysis Support: http://groups.yahoo.com/group/dialysis_support is a moderated online support group for people with kidney disease and those who care about them.

E

Equal Employment Opportunity Commission (EEOC): www.eeoc.gov (800) 669-4000 (TDD 1-800-669-6820) The EEOC is responsible for assuring that people are not discriminated against in employment due to their race, color, religion, sex, national origin, or disability status. The website offers information and forms to file an EEOC complaint.

Equal Pay Act of 1963 (EPA): www.eeoc.gov/laws/epa.html protects men and women who perform substantially equal work in the same establishment from sex-based wage discrimination.

F

Family and Medical Leave Act of 1993 (FMLA): www.dol.gov/dol/allcfr/ESA/Title_29/Part_825/toc.htm protects people with serious health conditions requiring medical treatment who have worked at least a year for an employer with 50 or more employees within a 75 mile radius of the workplace.

Forum of ESRD Networks: www.esrdnetworks.org (804) 794-2586 is the membership organization for 18 Networks. Medicare regulations mandate that in addition to other activities Networks should promote access to treatment settings most appropriate with vocational rehabilitation and encourage those with kidney failure, service providers, and facilities to participate in VR programs. How Networks do this varies from Network to Network. Many have rehabilitation committees, hold educational seminars, and are aware of educational resources available in the states they cover. Networks receive and process grievances about dialysis facilities and/or personnel. The website offers:

- Annual report on Network activities including vocational rehabilitation
- Map showing ESRD Networks with a link to each one
- Links to two different search engines for locating dialysis facilities

Forward Bound: NKF of MS (601) 981-3611 or E-mail: NKFMS@worldnet.att.net promotes rehabilitation of people between the ages of 19 and 40.

H

Health Care Financing Administration (HCFA): www.hcfa.gov has useful information on a variety of topics related to programs administered by HCFA.

- www.hcfa.gov/medicaid/twwiia/twwiiahp.htm offers information on the Ticket to Work and Work Incentives Improvement Act.

- www.hcfa.gov/medicaid/twwiia/comchart.htm offers a table of how states can implement expanded Medicaid coverage for those with disabilities who work.
- www.hcfa.gov/regions/roinfo.htm offers a list of the 10 HCFA regional offices

I

Independent Living Centers: www.designlinc.com/centers.htm provides a listing of all the IL centers in the USA. Independent Living Centers serve as advocates on a wide range of national, state, and local issues pertaining to people with disabilities. They work to assure physical and programmatic access to housing, employment, transportation, communities, recreational facilities, and health and social services.

International Center for the Disabled (ICD): (212) 585-6072 conducts research and has developed training materials specifically for employers, physicians, *Creating A Vocational Rehabilitation Program for Individuals on Renal Replacement Therapy: A Resource Manual.*

K

The **Kidney Transplant Dialysis Association (KD/TA):** (781) 641-4000 is a membership organization of those on dialysis or with transplants, family members, and professionals located in New England. Dedicated to providing financial aid, education, and support, the KT/DA publishes a regular newsletter, *RenalGram*, a handbook, and provides limited camp scholarships and scholarships for post-secondary education.

L

Life Options Rehabilitation Resource Center: www.lifeoptions.org (800) 468-7777 offers technical assistance and free educational materials on renal rehabilitation. Free information on the Internet includes Keys to a Long Life *Just the Facts* fact sheets, a *Goal setting Worksheet*, and *Patient Interest Checklists, Employment: A Guide to Work, Insurance and Finance for People on Dialysis*, bibliography references, success stories and tips, and much more.

M

Medicaid:

- www.hcfa.gov/medicaid/medicaid.htm is the Medicaid website and includes a search field that locates information about Medicaid through use of keys words
- www.hcfa.gov/medicaid/dualelig/resource.pdf is a resource directory with definitions of terms, acronyms, listings of State Health Insurance Assistance Programs, State Medicaid Offices, State Agencies on Aging, State Departments of Insurance, LIHEAP Coordinators and Tribal LIHEAP (Low-Income Home Energy Assistance Program) Coordinators, as well as State Distributing Agencies (nutrition programs)

Medication Assistance:

- at www.phrma.org/patients/ or in a searchable database on the Medicare website is where the *1999-2000 Directory of Prescription Drug Patient Assistance Programs* can be found. The directory can be obtained from the Pharmaceutical Research and Manufacturers Association (PhRMA) by calling (202) 835-3400.
- www.medicare.gov/Prescription/Home.asp is a database on the Medicare website that can be searched by state or region for medication assistance programs
- www.rxassist.org/ (877) 844-8442 for healthcare providers includes forms to submit for financial assistance for medications.

Medicare:

- www.medicare.gov/ provides publications on Medicare coverage
- www.medicare.gov/Publications/Pubs/pdf/esrdCoverage.pdf provides *Medicare Coverage of Kidney Dialysis and Kidney Transplant Services* (HCFA-10128) in English, large print version, and Spanish
- www.medicare.gov/Contacts/Home.asp offers *Helpful Contacts* for general information, reporting quality of care concerns and complaints, general health information, billing, information on health care facilities in the area and self-help groups by state

Medigap (Medicare Supplement) Plans: offer secondary coverage for

Medicare covered services. Although some offer prescription coverage (usually requires underwriting) and coverage outside the United States, most do not.

Medigap Compare: www.medicare.gov/mgcompare/home.asp provides a searchable database of Medigap plans offered in any state

N

National Council on Disability (NCD): www.ncd.gov

Each **ADA Disability & Business Technical Assistance Center** (800) 949-4232 provides businesses, government entities, and the public with information, materials, and technical assistance regarding the Americans with Disabilities Act. A site map of DBTCs is located at www.adata.org/index-dbtac.html.

- Region 1 – **New England Disability & Business Technical Assistance Center** (CT, ME, MA, NH, RI, VT), Adaptive Environments Center, Inc., 374 Congress Street, Suite 301, Boston, MA 02210 (617) 695-0085 (V/TTY), (617) 482-8099 (Fax), Email: adaptive@adaptenv.org Website: www.adaptenv.org.
- Region II – **Northeast Disability & Business Technical Assistance Center** (NJ, NY, PR, VI), United Cerebral Palsy Associations of New Jersey, 354 South Broad Street, Trenton, NJ 08608, (609) 392-4004 (V), (609) 392-7044 (TTY), (609) 392-3505 (Fax), Email: dbtac@ucpanj.org, Website: www.disabilityact.com.
- Region III – **Mid-Atlantic Disability & Business Technical Assistance Center** (DE, DC, MD, PA, VA, WV), TransCen, Inc., 451 Hungerford Drive, Suite 607, Rockville, MD 20850, (301) 217-0124 (V/TTY), (301) 217-0754 (Fax), Email: adainfo@transcen.org, Website: www.adainfo.org.
- Region IV – **Southeast Disability & Business Technical Assistance Center** (AL, FL, GA, KY, NC, SC, MS, TN), UCP National, Center for Rehabilitation Technology at Georgia Tech, 490 Tenth Street, Atlanta, GA 30318, (404) 385-0636 (V/TTY), (404) 385-0641 (Fax), Email: se-dbtac@mindspring.com, Website: www.sedbtac.org.
- Region V – **Great Lakes Disability & Business Technical Assistance Center** (IL, IN, MI, MN, OH,WI), University of Illinois/Chicago, Department on Disability & Human Development, 1640 West Roosevelt Road, Chicago, IL 60608, (312) 413-1407 (V/TTY), (312) 413-1856 (Fax), Email: gldbtac@uic.edu, Website:

www.adagreatlakes.org.

- Region VI – **Southwest Disability & Business Technical Assistance Center** (AR, LA, NM, OK, TX), Independent Living Research Utilization, 2323 South Shepherd Boulevard, Suite 1000, Houston, TX 77019, (713) 520-0232 (V/TTY), (713) 520-5785 (Fax), Email: ilru@ilru.org, Website: www.ilru.org/dbtac.
- Region VII – **Great Plains Disability & Business Technical Assistance Center** (IA, KS, MO, NE), ADA Project, University of Missouri/Columbia, 100 Corporate Lake Drive, Columbia, MO 65203, (573) 882-3600 (V/TTY), (573) 884-4925 (Fax), Email: adalh@showme.missouri.edu, Website: www.adaproject.org.
- Region VIII – **Rocky Mountain Disability & Business Technical Assistance Center** (CO, MT, ND, SD, UT, WY), Meeting the Challenge, Inc., 3630 Sinton Road, Suite 103, Colorado Springs, CO 80907, (719) 444-0268 (V/TTY), (719) 444-0269 (Fax), Email: RegionVIII@mtc-inc.com, Website: www.ada-infonet.org.
- Region IX – **Pacific Disability & Business Technical Assistance Center** (AZ, CA, HI, NV, Pacific Basin), California Public Health Institute, 2168 Shattuck Avenue, Suite 301, Berkeley, CA 94704-1307, (510) 848-2980 (V), (510) 848-1840 (TTY), (510) 848-1981 (Fax), Email: adatech@pdbtac.com, Website: www.pacdbtac.org.
- Region X – **Northwest Disability & Business Technical Assistance Center** (AK, ID, OR, WA), Washington State Governor's Committee on Disability Issues & Employment, P.O. Box 9046, MS 6000, Olympia, WA 98507-9046, (360) 438-4116 (V/TTY), (360) 438-3208 (Fax), Email: dcolley@esd.wa.gov, Website: www.wata.org/NWD.

National Kidney Disease Education Program (NKDEP): (301) 594-1932 was established to develop a coordinated national program to educate those with kidney disease and healthcare providers to reduce the morbidity and mortality caused by kidney disease.

National Kidney Foundation (NKF): www.kidney.org (800) 622-9010 provides educational and supportive meetings, programs and materials for people with kidney disease, their family members and providers; promotes quality of care development and dissemination of guidelines; funds research; and advocates for community services for people with kidney disease and for federal and state policies that promote quality care and quality of life. NKF offers programs that promote rehabilitation, such as **People Like Us, Live!** and **Rehabilitation, Information, Support and Empowerment (RISE)** plus numerous publications on the kidney, kidney disease, prevention, and treatment. NKF also publishes several brochures on rehabilitation topics such as working, exercise, and coping. NKF publishes a directory of camps for children and families, *Family Focus* and *Transplant Chronicles* and *For Those Who Give and Grieve* newsletters. In addition, NKF offers one brochure for VR counselors who work with people with kidney disease and a brochure for employers. NKF's constituent councils include the **Patient & Family Council** (people with kidney disease), **TransAction Council** (transplant recipients), and the **Donor Family Council** (those who have donated organs). **NKF affiliates** (www.kidney.org/general/affiliates/affaff.cfm) offer education and programs to help those with kidney disease, professionals, and the public. Affiliates also fund research and advocate for community services to fill unmet needs.

National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC): www.niddk.nih.gov/health/kidney/nkudic.htm (301) 654-4415 publishes print and posts on the Internet materials on kidney function, behaviors and conditions that lead to kidney disease and failure, preventive strategies, diet, and options for treatment of kidney failure. (See also Combined Health Information Database).

National Organization for State Kidney Programs: offers a directory of state kidney programs that is available by contacting the director of the Missouri Kidney Program at (800) 733-7345.

Nephron Information Center: www.nephron.com provides information on pre-dialysis (*Fadem's Kidney Guide*), quality of care guidelines (*Kidney Disease Outcomes Quality Initiative*), helpful Internet links (*Dialysis Patients Health Guide*), a searchable database of facilities based on HCFA data.

Networks

- **ESRD Network of New England** (CT, ME, MA, NH, RI, VT), PO Box 9484, New Haven, CT 06534, (203) 387-9332, FAX (203) 389-9902, Email: jkitsen@nw1.esrd.net
- **ESRD Network of New York** (NY), 1249 Fifth Avenue, A-419, New York, NY 10029, (212) 289-4524, Fax: (212) 289-4732, Email: grasmussen@nw2.esrd.net
- **TransAtlantic Renal Council** (NJ, PR, VI), Cranbury Gates Office Park, 109 S Main Street, Suite 21, Cranbury, NJ 08512, (609) 490-0310, Fax: (609) 490-0835, Email: jsolanchick@nw3.esrd.net

- **ESRD Network Org #4** (DE, MD), 200 Lothrop Street, Pittsburgh, PA 15213-2582, (412) 647-3428, Fax: (412) 683-6814, Email: bfreed@nw4.esrd.net
- **Mid-Atlantic Renal Coalition** (VA, WV, MD, DC), 1527 Huguenot Road, Midlothian, VA 23113, (804) 794-3757, Fax: (804) 794-3793, Email: marc@nw5.esrd.net
- **Southeastern Kidney Council** (GA, NC, SC), 1000 St. Albans Drive # 270, Raleigh, NC 27609, (919) 788-8112, Fax:(919) 788-9399, Email: jkrisher@nw6.esrd.net
- **ESRD Network of Florida** (FL), One Davis Boulevard, Suite 304, Tampa, FL 33606, (813) 251-8686, Fax:(813) 251-3744, Email: rmizzoni@nw7.esrd.net
- **Network 8, Inc.** (AL, MS, TN), PO Box 55868, Jackson, MS 39296-5868, (601) 936-9260, Fax: (601) 932-4446, Email: jfuller@nw8.esrd.net
- **The Renal Network** (IL, IN, KY, OH), 911 East 86th Street, Suite 202, Indianapolis, IN 46240, (317) 257-8265, Fax: (317) 257-8291, Email: sstark@nw10.esrd.net
- **Renal Network of the Upper Midwest, Inc.** (MN, MI, ND, SD, WI), 970 Raymond Avenue # 205, St. Paul, MN 55114, (651) 644-9877, Fax: (651) 644-9853, Email: dcarlson@nw11.esrd.net
- **ESRD Network #12** (IA, KS, MO, NE), 7505 NW Tiffany Springs Pkwy, Suite 230, Kansas City, MO 64153, (816) 880-9990, Fax: (816) 880-9088, Email: ltaylor@nw12.esrd.net
- **ESRD NW Organization #13** (AR, LA, OK), 6600 N Meridian Ave, Suite 155, Oklahoma City, OK 73116, (405) 843-8688, Fax: (405) 842-4097, Email: pphilliber@nw13.esrd.net
- **ESRD Network of Texas** (TX), 14114 Dallas Pkwy, Suite 660, Dallas, TX 75240, (972) 503-3215, Fax: (9172) 503-3219, Email: gharbert@nw14.esrd.net
- **Intermountain ESRD Network** (AZ, CO, NV, NM, UT, WY), 1301 Pennsylvania Ave, Suite 750, Denver, CO 80203-5012, (303) 831-8818, Fax: (303) 860-8392, Email: sstiles@nw15.esrd.net
- **Northwest Renal Network** (AK, ID, MT, OR, WA), 4702 42nd Avenue, SW, Seattle, WA 98116, (206) 923-0714, Fax: (206) 923-0716, Email: llawson@nw16.esrd.net
- **TransPacific Renal Network** (AS, GU, Mariana Islands, HI, N CA), 25 Mitchell Boulevard Suite 7, San Rafael, CA 94903, (415) 472-8590, Fax: (415) 472-8594, Email: asukloksy@nw17.esrd.net
- **Southern California Renal Disease Council** (S CA), 6255 Sunset Boulevard, Suite 2211, Los Angeles, CA 90028, (323) 962-2020, Fax:

(323) 962-2891, Email: dmarsh@nw18.esrd.net

P

People Like Us, Live! is a program offered through National Kidney Foundation affiliates that provides support and group education for people with kidney disease and their families about kidney disease, options for treatment, diet, and finances and coping.

Pharmaceutical Assistance Programs (see Medication Assistance)

Polycystic Kidney Research Foundation: www.pkdcure.org (800) 753-2873 funds research on polycystic kidney disease, provides education, and publishes *The PKD Patients' Manual*, *Q & A on PKD, and The Family and ADPKD: A Guide for Children and Parents.*

Project ACTION: www.projectaction.org/paweb/index.htm#welcome (202) 347-3066 provides a database of transportation for people with disabilities living in urban and rural communities

R

Rehabilitation Act of 1973 Section 501 www.eeoc.gov/laws/rehab.html prohibits discrimination against qualified people in the federal government. Section 504 of the Rehabilitation Act of 1973 prohibits employment in any program that receives federal funds or in any government agency, including the U.S. Postal Service www.dol.gov/dol/oasam/public/regs/statutes/sec504.htm.

Renal Physicians Association: www.renalmd.org has a committee that focuses on issues of those with kidney disease. The RPA has developed two clinical practice guidelines: *Shared Decision Making in the Initiation and Withdrawal from Dialysis*, and *Appropriate Patient Preparation for Renal Replacement Therapy*, the later includes information on rehabilitation.

Renal Support Network: www.renalnetwork.org offers online support

RENALNET: www.renalnet.org provides a clearinghouse for information on the cause, treatment, and management of kidney disease and kidney failure.

RenalWEB: www.renalweb.com offers discussion boards, dialysis industry information, and education.

RISE (Rehabilitation: Information, Support & Empowerment): www.kidney.org/patients/rise.cfm (800) 622-9010 is offered through National Kidney Foundation Affiliates. This program supports productive living for people with chronic kidney disease (CKD) by assessing vocational interests, skills, and values and providing information about volunteer opportunities and educational and vocational programs and services offered by federal and state agencies (see Toolkit for more information)

Road Commission of the Department of Transportation (DOT) can make those on dialysis a priority in snow emergencies, especially in rural areas.

S

Social Security Administration: www.ssa.gov/ (800) 773-1213 or (800) 325-0778 (TTY) Hours: 7 a.m.- 7 p.m. EST.

- Determines eligibility for SSI and SSDI programs;
- Determines whether SSI beneficiaries are eligible for PASS and Section 1619(a) [sliding scale reduction in cash disability benefits] and (b) [continuation of Medicaid benefits];
- Determines whether SSI and SSDI beneficiaries' medical expenses can be considered impairment-related (or blind) work expenses;
- Accepts applications for Medicare
- Provides printed and Internet information on Social Security retirement and disability benefits as well as information programs that help people with disabilities obtain or maintain employment.

Springboard is a program offered by the National Kidney Foundation of Georgia [www.nkfg.org (770) 452-1539 or (800) 633-2339 (Georgia)] for people 19-30 that could be used as a model in other areas (see Toolkit for more information).

State Health Insurance Assistance Program (SHIP) is available in every state to answer general questions about health insurance, Medicare, Medigap policies, or to file an appeal. Information can be found on the Medicare website "Contacts" page at www.medicare.gov/Contacts/Home.asp or in *Medicare Coverage of Kidney Dialysis and Kidney Transplant Services* (Publication No. HCFA – 10128)

State Kidney Programs (see National Organization for State Kidney Programs)

T

Ticket to Work and Work Incentives Improvement Act of 1999: www.ssa.gov/work/ResourcesToolkit/legisreg2.html provides the law, regulations, fact sheets, questions and answers, information on Medicare extension, and even a PowerPoint Presentation on TTWWIIA.

- Provides a phased-in program in which people with disabilities receive vouchers to obtain services from employment networks
- Extends Medicare coverage for a total of 8.5 years for people with disabilities who work
- Encourages states to expand Medicaid coverage for people with disabilities who work www.hcfa.gov/medicaid/twwiia/statemap.htm.
- Expedites reinstatement of Social Security disability benefits in the case of a health setback
- Postpones re-determination of disability for those with disabilities as long as they're using the "tickets"
- Establishes funding for demonstration projects for innovative programming to promote improved employment outcomes for people with disabilities, including one that is studying a sliding scale reduction of benefits for SSDI recipients similar to what is available for SSI beneficiaries.

Transplant Recipients International Organization (TRIO): www.trioweb.org/resources/helpingear.html (800) 874-6386 offers support groups in some communities

Transplant Springboard (see Springboard)

Transportation Equity Act: www.fhwa.dot.gov/tea21/factsheets/index.htm provides a list of fact sheets including information on Job Access and Reverse Commute grants, Department of Transportation (DOT) grants for people with disabilities and elderly, paratransit services under the ADA, plus the DOT's On the Job Training and Welfare to Work programs. Information on Job Access and Reverse Commute 2000 projects by state and municipality can be found at www.fta.dot.gov/wtw/jarcp00.html.

Transportation Providers can include public, commercial, and volunteer groups that provide dialysis-related transportation. Access to reliable transportation impacts those on dialysis vocationally and medically. Social workers in dialysis and transplant programs generally know these resources.

TRICARE: http://tricare.osd.mil/TricareHandbook/ United Concordia Companies, Inc., (800) 866-8499 provides healthcare coverage for active duty and retired military and their families.

U

United Network For Organ Sharing: www.unos.org (888) 894-6361 provides a wealth of information including education about the "list," the transplant process, and facility-specific data on transplant outcomes.

United States Renal Data System: www.usrds.org (888) 99-USRDS provides data on incidence, prevalence, cost of care, facility characteristics, characteristics of those with kidney failure, and employment 6 months pre-treatment and at the initiation of dialysis or transplant.

United Way of America: http://national.unitedway.org/ (703) 836-7100, offers community building; emergency food and shelter to supplements the work of local private and governmental social service organizations; the letter carrier's National Food Drive, and Project Blueprint that seeks greater involvement of minorities as volunteer leaders and policy makers in the United Way system.

V

Vocational Rehabilitation: www.ssa.gov/work/ServiceProviders/rehabproviders2.html can help unemployed clients obtain education and vocational skills and/or find full or part-time employment and help clients maintain employment and by helping current employers understand accommodation needs and the cost benefits of keeping a valued employee. If a VR office cannot provide services, a list of approved alternate participants by state can be found at www.ssa.gov/work/ServiceProviders/altpartstatlist.html.

W

Workforce Investment Act (WIA) (http://usworkforce.org/finalrule.htm) establishes the one-stop employment service delivery systems that provide one point of access to all the employment resources available through many agencies with the objective being to provide easy access job seekers to all employment-related services. Whether someone requires training, vocational rehabilitation, interview preparation, job-search assistance, or any other support in getting a job they can receive the service at the One-Stop Center. Because many people with kidney disease lack the transportation resources and the patience to go from agency to agency, having all employment-related services in one location should increase access to these services.

Toolkit

Toolkit

Kidney Diseases Dictionary

From the National Kidney and Urologic Diseases Information Clearinghouse

A

acute (uh-KYOOT)**:** Acute often means urgent. An acute disease happens suddenly. It lasts a short time. Acute is the opposite of ***chronic***, or long lasting.

acute renal (REE-nul) **failure:** A condition in which the ***kidneys*** suddenly stop working. In most cases, kidneys can recover from almost complete loss of function.

acute tubular (TOO-byoo-lur) **necrosis** (neh-KRO-sis) **(ATN):** A severe form of ***acute renal failure*** that develops in people with severe illnesses like infections or with low blood pressure. Patients may need ***dialysis***. ***Kidney*** function often improves if the underlying disease is successfully treated.

albuminuria (AL-byoo-mih-NOO-ree-uh)**:** More than normal amounts of a protein called albumin in the ***urine***. Albuminuria may be a sign of ***kidney*** disease.

allograft (AL-oh-graft)**:** An organ or tissue ***transplant*** between two humans.

Alport syndrome (AL-port SIN-drome)**:** An inherited condition that results in ***kidney*** disease. It generally develops during early childhood and is more serious in boys than in girls. The condition can lead to ***end-stage renal disease***, as well as hearing and vision problems. The common symptoms of this condition are ***chronic*** blood and protein in the ***urine***.

Amyloidosis (AM-ih-loy-DOH-sis)**:** A condition in which a protein-like material builds up in one or more organs. This material cannot be broken down and interferes with the normal function of that organ. In ***kidneys***, amyloidosis can lead to ***proteinuria***, ***nephrotic syndrome***, and ***renal*** failure.

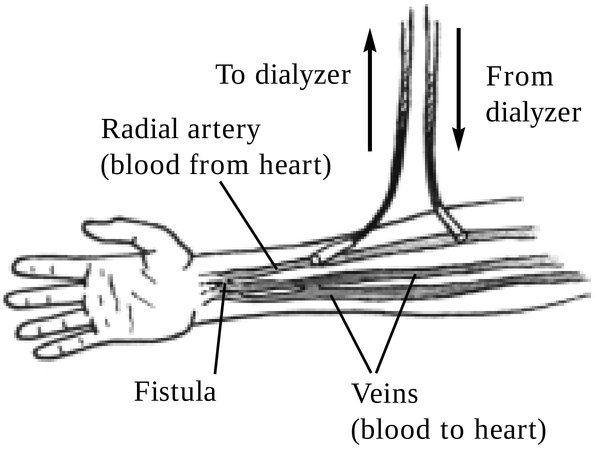
analgesic(AN-ul-JEE-zik)**-associated kidney disease:** Loss of ***kidney*** function that results from long-term use of analgesic (pain-relieving) medications. Analgesics that combine aspirin and acetaminophen are most dangerous to the kidneys.

anemia (uh-NEE-mee-uh)**:** The condition of having too few red blood cells. Healthy red blood cells carry oxygen throughout the body. If the blood is low on red blood cells, the body does not get enough oxygen. People with anemia may be tired and pale and may feel their heartbeat change. Anemia is common in people with ***chronic renal failure*** or those on ***dialysis***. (See also ***erythropoietin***.)

antidiuretic (AN-tee-DY-uh-RET-ik) **hormone (ADH):** A natural body chemical that slows down the ***urine*** flow. Some children who wet their beds regularly may lack normal amounts of antidiuretic hormone.

anuria (uh-NYOOR-ee-uh)**:** A condition in which the person stops making ***urine***.

arteriovenous (ar-TEER-ee-oh-VEE-nus) **(AV) fistula** (FIST-yoo-luh)**:** Surgical connection of an artery directly to a vein, usually in the forearm, created in patients who will need ***hemodialysis*** (see ***dialysis***). The AV fistula causes the vein to grow thicker, allowing the repeated needle insertions required for hemodialysis.



Arteriovenous Fistula

autoimmune (AW-toh-ih-MYOON) **disease:** Any disorder in which the body is attacked by its own ***immune system***. Examples are ***Goodpasture syndrome*** and lupus erythematosus (see ***lupus nephritis***).

B

biopsy (BY-op-see)**:** A procedure in which a tiny piece of a body part, such as the ***kidney*** or ***bladder***, is removed for examination under a microscope.

bladder (BLAD-ur)**:** The balloon-shaped organ inside the ***pelvis*** that holds ***urine***.

blood urea (yoo-REE-uh) **nitrogen** (NY-truh-jen) **(BUN):** A waste product in the blood that comes from the breakdown of food protein. The ***kidneys*** filter blood to remove urea. As kidney function decreases, the BUN level increases.

C

calcium (KAL-see-um)**:** A mineral that the body needs for strong bones and teeth. Calcium may form stones in the ***kidney***.

chronic (KRAH-nik)**:** Lasting a long time. Chronic diseases develop slowly. ***Chronic renal failure*** may develop over many years and lead to ***end-stage renal disease***.

chronic renal (REE-nul) **failure:** Slow and progressive loss of ***kidney*** function over several years, often resulting in ***end-stage renal disease***. People with end-stage renal disease need dialysis or transplantation to replace the work of the kidneys.

creatinine (kree-AT-ih-nin)**:** A waste product from meat protein in the diet and from the muscles of the body. Creatinine is removed from blood by the ***kidneys***; as kidney disease progresses, the level of creatinine in the blood increases.

creatinine clearance: A test that measures how efficiently the ***kidneys*** remove ***creatinine*** and other wastes from the blood. Low creatinine clearance indicates impaired kidney function.

cyst (SIST)**:** An abnormal sac containing gas, fluid, or a semisolid material. Cysts may form in ***kidneys*** or in other parts of the body.

cystine (SIS-teen)**:** An amino acid found in blood and urine. Amino acids are building blocks of protein. (See also ***cystine stone*** and ***cystinuria***.)

cystine stone: A rare form of ***kidney stone*** consisting of the amino acid ***cystine***.

cystinuria (SIS-tih-NOO-ree-uh)**:** A condition in which ***urine*** contains high levels of the amino acid cystine. If cystine does not dissolve in the urine, it can build up to form ***kidney stones***.

cystitis (sis-TY-tis)**:** Inflammation of the ***bladder***, causing pain and a burning feeling in the ***pelvis*** or ***urethra***.

cystoscope (SIS-tuh-skope)**:** A tool for examining the bladder. The procedure is called cystoscopy (sis-TAH-skuh-pee).

D

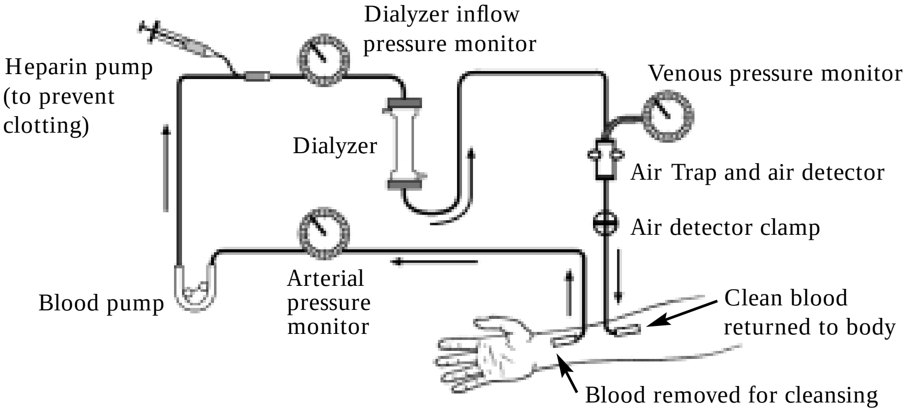
diabetes (dy-uh-BEE-teez) **insipidus** (in-SIP-ih-dus)**:** A condition characterized by frequent and heavy urination, excessive thirst, and an overall feeling of weakness. This condition may be caused by a defect in the pituitary gland or in the kidney. In diabetes insipidus, blood sugar levels are normal. (See also ***nephrogenic diabetes insipidus***.)

diabetes (dy-uh-BEE-teez) **mellitus** (MELL-ih-tus)**:** A condition characterized by high blood sugar resulting from the body's inability to use sugar (glucose) efficiently. In type 1 diabetes, the pancreas is not able to make enough insulin; in type 2 diabetes, the body is resistant to the effects of available insulin.

dialysate (dy-AL-ih-sate)**:** A cleansing liquid used in the two major forms of ***dialysis*** — hemodialysis and peritoneal dialysis.

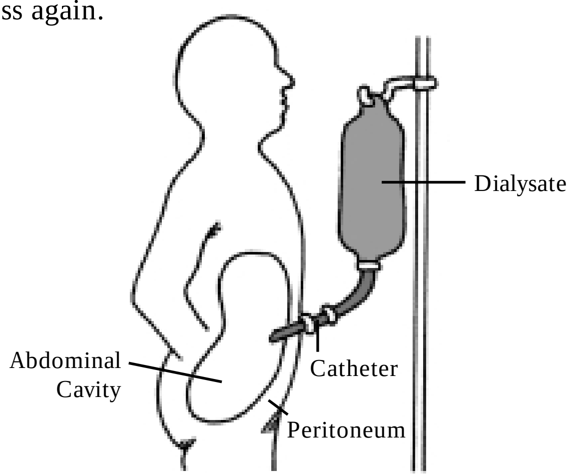
dialysis (dy-AL-ih-sis)**:** The process of cleaning wastes from the blood artificially. This job is normally done by the kidneys. If the kidneys fail, the blood must be cleaned artificially with special equipment. The two major forms of dialysis are hemodialysis and peritoneal dialysis.

- **hemodialysis** (HEE-moh-dy-AL-ih-sis)**:** The use of a machine to clean wastes from the blood after the ***kidneys*** have failed. The blood travels through tubes to a ***dialyzer***, which removes wastes and extra fluid. The cleaned blood then flows through another set of tubes back into the body.



Hemodialysis

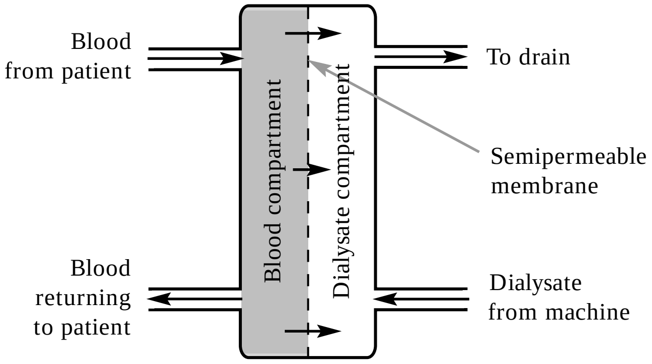
- **peritoneal** (PEH-rih-tuh-NEE-ul) **dialysis:** Cleaning the blood by using the lining of the belly (abdomen) as a filter. A cleansing solution, called ***dialysate***, is drained from a bag into the belly. Fluids and wastes flow through the lining of the belly and remain “trapped” in the dialysate. The dialysate is then drained from the belly, removing the extra fluids and wastes from the body. There are three types of peritoneal dialysis:
- **continuous ambulatory** (AM-byoo-luh-TOH-ree) **peritoneal dialysis (CAPD):** The most common type of peritoneal dialysis. It needs no machine. With CAPD, the blood is always being cleaned. The ***dialysate*** passes from a plastic bag through the catheter and into the abdomen. The ***dialysate*** stays in the abdomen with the catheter sealed. After several hours, the person using CAPD drains the solution back into a disposable bag. Then the person refills the abdomen with fresh solution through the same catheter, to begin the cleaning process again.



CAPD and IPD

- **continuous cyclic** (SYKE-lik or SIK-lik) **peritoneal dialysis (CCPD):** A form of peritoneal dialysis that uses a machine. This machine automatically fills and drains the dialysate from the abdomen. A typical CCPD schedule involves three to five ***exchanges*** during the night while the person sleeps. During the day, the person using CCPD performs one exchange with a ***dwell time*** that lasts the entire day.
- **nocturnal** (nok-TURN-ul) **intermittent** (IN-ter-MIT-unt) **peritoneal dialysis (NIPD):** A machine-aided form of peritoneal dialysis. NIPD differs from CCPD in that six or more ***exchanges*** take place during the night, and the NIPD patient does not perform an exchange during the day.

dialyzer (DY-uh-LY-zur)**:** A part of the ***hemodialysis*** machine. (See ***hemodialysis*** under ***dialysis***.) The dialyzer has two sections separated by a ***membrane***. One section holds ***dialysate***. The other holds the patient's blood.



Dialyzer

dwell time: In peritoneal ***dialysis***, the amount of time a bag of ***dialysate*** remains in the patient's abdominal cavity during an ***exchange***.

E

edema (eh-DEE-muh)**:** Swelling caused by too much fluid in the body.

electrolytes (ee-LEK-troh-lites)**:** Chemicals in the body fluids that result from the breakdown of salts, including sodium, potassium, magnesium, and chloride. The ***kidneys*** control the amount of electrolytes in the body. When the kidneys fail, electrolytes get out of balance, causing potentially serious health problems. ***Dialysis*** can correct this problem.

end-stage renal (REE-nul) **disease (ESRD):** Total chronic ***kidney*** failure. When the kidneys fail, the body retains fluid and harmful wastes build up. A person with ESRD needs treatment to replace the work of the failed kidneys.

erythropoietin (eh-RITH-roh-POY-uh-tin)**:** A ***hormone*** made by the ***kidneys*** to help form red blood cells. Lack of this hormone may lead to ***anemia***.

ESRD: ***end-stage renal disease.***

ESWL: ***extracorporeal shockwave lithotripsy.***

exchange: A cycle in peritoneal ***dialysis*** in which the patient fills the abdominal cavity with ***dialysate***, carries it for a specified ***dwell time***, and then empties the dialysate from the abdomen in preparation for a fresh bag of dialysate.

extracorporeal (EKS-truh-kor-POR-ee-ul) **shockwave lithotripsy** (LITH-oh-TRIP-see) **(ESWL):** A nonsurgical procedure using shock waves to break up ***kidney stones.***

F

fistula (FIST-yoo-lah)**:** See ***arteriovenous fistula***.

G

glomeruli (gloh-MEHR-yoo-lie)**:** Plural of ***glomerulus***.

glomerulonephritis (gloh-MEHR-yoo-loh-nef-RY-tis)**:** Inflammation of the ***glomeruli***. Most often, it is caused by an ***autoimmune disease***, but it can also result from infection.

glomerulosclerosis (gloh-MEHR-yoo-loh-skleh-ROH-sis)**:** Scarring of the ***glomeruli***. It may result from ***diabetes mellitus*** (diabetic glomerulosclerosis) or from deposits in parts of the ***glomerulus*** (focal segmental glomerulosclerosis). The most common signs of glomerulosclerosis are ***proteinuria*** and ***kidney*** failure.

glomerulus (gloh-MEHR-yoo-lus)**:** A tiny set of looping blood vessels in the ***nephron*** where blood is filtered in the ***kidney***.

Goodpasture syndrome: An uncommon disease that usually includes bleeding from the lungs, coughing up of blood, and inflammation of the kidneys that can lead to kidney failure. This condition is an ***autoimmune disease***.

H

hematocrit (hee-MAT-uh-krit)**:** A measure that tells how many red blood cells are present in a blood sample. Low hematocrit suggests ***anemia*** or massive blood loss.

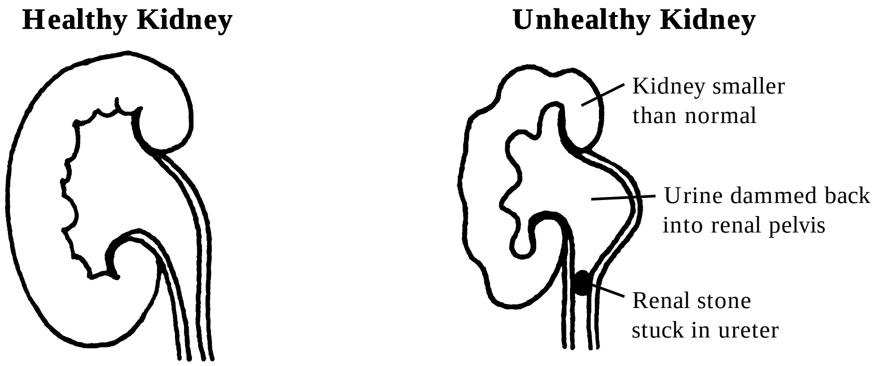
hematuria (HEE-muh-TOOR-ee-uh)**:** Blood in the ***urine***, which can be a sign of a ***kidney stone***, ***glomerulonephritis***, or other kidney problem.

hemodialysis: See ***dialysis***.

hemolytic (HEE-moh-LIT-ik) **uremic** (yoo-REE-mik) **syndrome** (SIN-drome) **(HUS):** A disease that affects the blood and blood vessels. It destroys red blood cells, cells that cause the blood to clot, and the lining of blood vessels. HUS is often caused by the *Escherichia coli* bacterium in contaminated food. People with HUS may develop ***acute renal failure***.

hormone (HOR-mone)**:** A natural chemical produced in one part of the body and released into the blood to trigger or regulate particular functions of the body. The ***kidney*** releases three hormones: ***erythropoietin***, ***renin***, and an active form of vitamin D that helps regulate ***calcium*** for bones.

hydronephrosis (HY-droh-nef-ROH-sis)**:** Swelling of the top of the ureter, usually because something is blocking the ***urine*** from flowing into or out of the ***bladder***.


Healthy Kidney

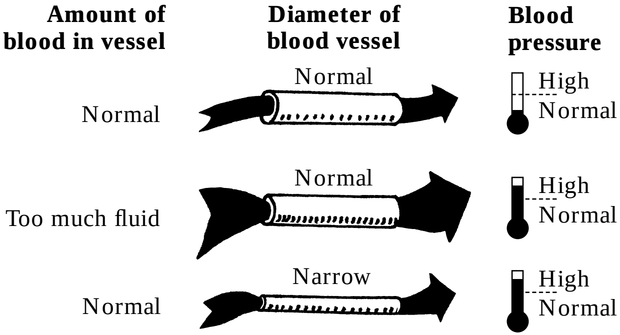
Unhealthy Kidney

Hydronephrosis

hypercalciuria (HY-per-kal-see-YOO-ree-uh)**:** Abnormally large amounts of ***calcium*** in the ***urine***.

hyperoxaluria (HY-per-ox-uh-LOO-ree-uh)**:** Unusually large amounts of ***oxalate*** in the ***urine***, leading to ***kidney stones***.

hypertension (HY-per-TEN-shun)**:** High blood pressure, which can be caused either by too much fluid in the blood vessels or by narrowing of the blood vessels.



Hypertension

I

IgA nephropathy (nef-RAHP-uh-thee)**:** A ***kidney*** disorder caused by deposits of the protein immunoglobulin A (IgA) inside the ***glomeruli*** (filters) within the kidney. The IgA protein damages the glomeruli, leading to blood and protein in the ***urine***, to swelling in the hands and feet, and sometimes to kidney failure.

immune (im-YOON) **system:** The body's system for protecting itself from viruses and bacteria or any "foreign" substances.

immunosuppressant (im-YOON-oh-suh-PRESS-unt)**:** A drug given to suppress the natural responses of the body's ***immune system***. Immunosuppressants are given to transplant patients to prevent organ rejection and to patients with ***autoimmune diseases*** like lupus.

interstitial (IN-ter-STISH-ul) **nephritis** (nef-RY-tis)**:** Inflammation of the kidney cells that are not part of the fluid-collecting units, a condition that can lead to ***acute renal failure*** or ***chronic renal failure***.

intravenous (IN-truh-VEE-nus) **pyelogram** (PY-loh-gram)**:** An x-ray of the ***urinary tract***. A dye is injected to make the ***kidney***, ***ureters,*** and ***bladder*** visible on the x-ray and show any blockage in the urinary tract.

K

kidneys (KID-neez)**:** The two bean-shaped organs that filter wastes from the blood. The kidneys are located near the middle of the back. They create ***urine***, which is delivered to the ***bladder*** through tubes called ***ureters***.

kidney stone: A stone that develops from crystals that form in ***urine*** and build up on the inner surfaces of the ***kidney***, in the ***renal pelvis***, or in the ***ureters***.

Kt/V (kay-tee over vee)**:** A measurement of ***dialysis*** dose. The measurement takes into account the efficiency of the ***dialyzer***, the treatment time, and the total volume of ***urea*** in the body. See also ***URR***.

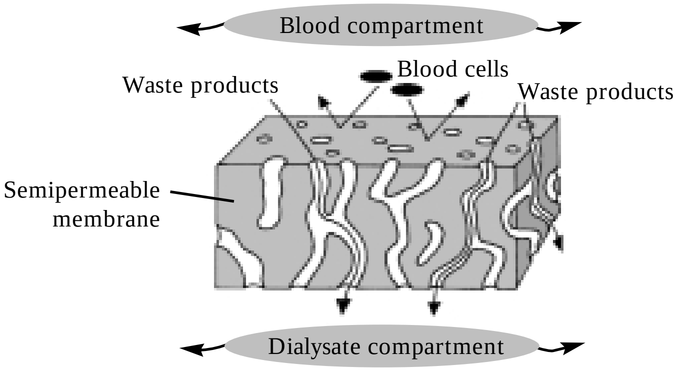
L

lithotripsy (LITH-oh-TRIP-see)**:** A method of breaking up ***kidney*** stones using shock waves or other means.

lupus (LOO-pus) **nephritis** (nef-RY-tis)**:** Inflammation of the ***kidneys*** caused by an ***autoimmune disease*** called systemic lupus erythematosus (eh-rih-theh-mah-TOH-sis). The condition can cause ***hematuria*** and ***proteinuria***, and it may progress to ***end-stage renal disease***.

M

membrane (MEM-brane)**:** A thin sheet or layer of tissue that lines a cavity or separates two parts of the body. A membrane can act as a filter, allowing some particles to pass from one part of the body to another while keeping others where they are. The membrane in a ***dialyzer*** filters waste products from the blood.



Dialyzer Membrane

membranoproliferative (MEM-bray-no-pro-LIF-er-uh-tiv) **glomerulonephritis** (gloh-MEHR-yoo-loh-nef-RY-tis)**:** A disease that occurs primarily in children and young adults. Over time, inflammation leads to scarring in the ***glomeruli***, causing ***proteinuria***, ***hematuria***, and sometimes ***chronic renal failure*** or ***end-stage renal disease***.

N

nephrectomy (nef-REK-tuh-mee)**:** Surgical removal of a ***kidney***.

nephrogenic (NEF-roh-JEN-ik) **diabetes** (DY-uh-BEE-teez) **insipidus** (in-SIP-ih-dus)**:** Constant thirst and frequent urination because the ***kidney*** tubules cannot respond to ***antidiuretic hormone***. The result is an increase in ***urine*** formation and excessive urine flow.

nephrolithiasis (NEF-roh-lih-THY-uh-sis)**:** ***Kidney stones***.

nephrologist (nef-RAHL-oh-jist)**:** A doctor who treats patients with ***kidney*** problems or ***hypertension***.

nephron (NEF-rahn)**:** A tiny part of the ***kidneys***. Each kidney is made up of about 1 million nephrons, which are the working units of the kidneys, removing wastes and extra fluids from the blood.

nephrotic (nef-RAH-tik) **syndrome:** A collection of symptoms that indicate ***kidney*** damage. Symptoms include high levels of protein in the ***urine***, lack of protein in the blood, and high blood cholesterol.

nuclear (NEW-klee-ur) **scan:** A test of the structure, blood flow, and function of the ***kidneys***. The doctor injects a mildly radioactive solution into an arm vein and uses x-rays to monitor its progress through the kidneys.

O

oxalate (AHK-suh-late)**:** A chemical that combines with ***calcium*** in urine to form the most common type of ***kidney stone*** (calcium oxalate stone).

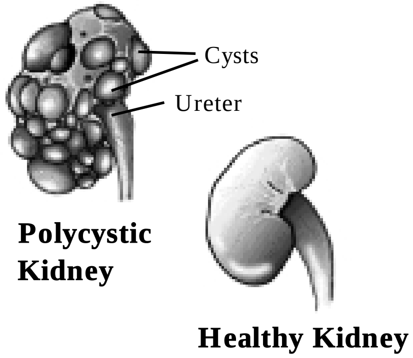
P

pelvis (PELL-vis)**:** The bowl-shaped bone that supports the spine and holds up the digestive, urinary, and reproductive organs. The legs connect to the body at the pelvis.

percutaneous (PER-kyoo-TAY-nee-us) **nephrolithotomy** (NEF-roh-lih-THAH-tuh-mee)**:** A method for removing ***kidney stones*** via keyhole surgery through the back.

peritoneal dialysis: See ***dialysis***.

polycystic (PAHL-ee-SIS-tik) **kidney disease (PKD):** An inherited disorder characterized by many grape-like clusters of fluid-filled cysts that make both ***kidneys*** larger over time. These cysts take over and destroy working kidney tissue. PKD may cause ***chronic renal failure*** and ***end-stage renal disease***.



proteinuria (PRO-tee-NOOR-ee-uh)**:** The presence of protein in the ***urine***, indicating that the ***kidneys*** are not working properly.

pyelonephritis (PY-loh-nef-RY-tis)**:** An infection of the ***kidney***(s), usually caused by a germ that has traveled up through the ***urethra***, ***bladder***, and ***ureter***(s) from outside the body.

R

renal (REE-nul)**:** Of the ***kidneys***. A renal disease is a disease of the kidneys. Renal failure means the kidneys have stopped working properly.

renal agenesis (ay-JEN-eh-sis)**:** The absence or severe malformation of one or both ***kidneys***.

renal cell carcinoma (KAR-sih-NOH-mah)**:** A type of ***kidney*** cancer.

renal cysts (SISTS)**:** Abnormal fluid-filled sacs in the ***kidney*** that range in size from microscopic to much larger. Many simple cysts are harmless, while other types can seriously damage the kidneys.

renal osteodystrophy (AH-stee-oh-DIS-truh-fee)**:** Weak bones caused by poorly working ***kidneys***. Renal osteodystrophy is a common problem for people on dialysis who have high phosphate levels or insufficient vitamin D supplementation.

renal pelvis (PELL-vis)**:** The basin into which the ***urine*** formed by the ***kidneys*** is excreted before it travels to the ureters and bladder.

renal tubular (TOOB-yoo-lur) **acidosis** (ASS-ih-DOH-sis)**:** A defect in the ***kidneys*** that hinders their normal excretion of acids. Failure to excrete acids can lead to weak bones, ***kidney stones***, and poor growth in children.

renal vein thrombosis (throm-BOH-sis)**:** Blood clots in the vessel that carries blood away from the ***kidney***. This can occur in people with the ***nephrotic syndrome***.

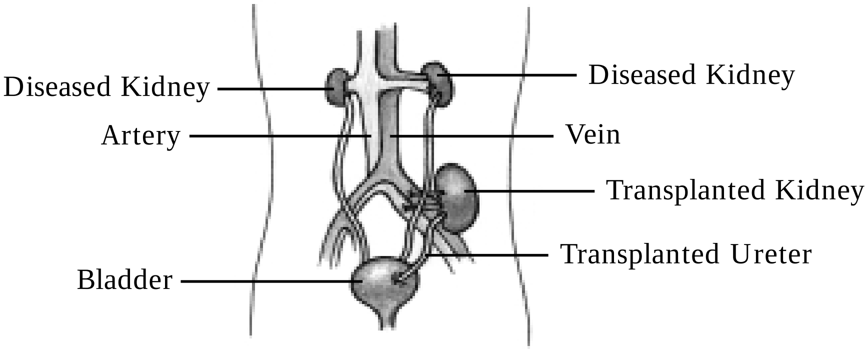
renin (REE-nin)**:** A hormone made by the ***kidneys*** that helps regulate the volume of fluid in the body and blood pressure.

S

struvite (STROO-vite) **stone:** A type of ***kidney stone*** caused by infection.

T

transplant (TRANZ-plant)**:** Replacement of a diseased organ with a healthy one. A kidney transplant may come from a living donor, usually a relative, or from someone who has just died.



U

ultrasound: A technique that bounces safe, painless sound waves off organs to create an image of their structure.

urea (yoo-REE-uh)**:** A waste product found in the blood and caused by the normal breakdown of protein in the liver. Urea is normally removed from the blood by the ***kidneys*** and then excreted in the ***urine***. Urea accumulates in the body of people with renal failure.

uremia (yoo-REE-mee-uh)**:** The illness associated with the buildup of urea in the blood because the ***kidneys*** are not working effectively. Symptoms include nausea, vomiting, loss of appetite, weakness, and mental confusion.

ureteroscope (yoo-REE-tur-uh-scope)**:** A tool for examining the ***bladder*** and ***ureters*** and for removing ***kidney stones*** through the urethra. The procedure is called ureteroscopy (yoo-ree-tur-AH-skoh-pee).

ureters (YOOR-uh-turs)**:** Tubes that carry ***urine*** from the ***kidneys*** to the ***bladder***.

urethra (yoo-REE-thrah)**:** The tube that carries ***urine*** from the ***bladder*** to the outside of the body.

uric (YOOR-ik) **acid stone:** A ***kidney stone*** that may result from a diet high in animal protein. When the body breaks down this protein, uric acid levels rise and can form stones.

urinalysis (yoor-in-AL-ih-sis)**:** A test of a urine sample that can reveal many problems of the urinary system and other body systems. The sample may be observed for color, cloudiness, concentration; signs of drug use; chemical composition, including sugar; the presence of protein, blood cells, or germs; or other signs of disease.

urinary (YOOR-ih-NEHR-ee) **tract:** The system that takes wastes from the blood and carries them out of the body in the form of ***urine***. The urinary tract includes the ***kidneys***, ***renal pelvises***, ***ureters***, ***bladder***, and ***urethra***.

urinary tract infection (UTI): An illness caused by harmful bacteria growing in the ***urinary tract***.

urinate (YOOR-ih-nate)**:** To release ***urine*** from the bladder to the outside.

urine (YOOR-in)**:** Liquid waste product filtered from the blood by the ***kidneys***, stored in the ***bladder***, and expelled from the body through the ***urethra*** by the act of ***voiding*** or ***urinating***.

urolithiasis (YOOR-oh-lih-THY-uh-sis)**:** Stones in the urinary system.

URR (urea reduction ratio): A blood test that compares the amount of ***blood urea nitrogen*** before and after ***dialysis*** to measure the effectiveness of the dialysis dose.

V

vasculitis (VAS-kyoo-LY-tis)**:** Inflammation of the blood vessel walls. This can cause rash and disease in multiple organs of the body, including the ***kidneys***.

vesicoureteral (VESS-ih-koh-yoo-REE-ter-ul) **reflux:** An abnormal condition in which ***urine*** backs up into the ***ureters***, and occasionally into the ***kidneys***, raising the risk of infection.

void: To ***urinate***, empty the ***bladder***.

W

Wegener's granulomatosis (GRAN-yoo-LOH-muh-TOH-sis): An ***autoimmune disease*** that damages the blood vessels and causes disease in the lungs, upper respiratory tract, and ***kidneys***.

When Is Medicare Primary Or Secondary Payer?

Initial Treatment Type	When Medicare Is Primary	When Employer Group Is Primary (Coordination Period)
In-center hemodialysis, disabled or not		
No employer group	4th mo on as long as dialysis continues	N/A
Employer group	34th mo on as long as dialysis continues	From 1st – 33rd mo
Home/self care dialysis, disabled or not		
No employer group	From 1st of mo dialysis as long as dialysis continues	N/A
Employer group	From 31st mo on as long as dialysis continues	From 1st – 30th mo
Transplant, disabled		
No employer group	From 2 mo pre-transplant through 36th mo if transplant occurs within 2 mo,	N/A
Employer group	From 31st mo on	From 1st – 30th mo
Transplant, not disabled		
No employer group	From 2 mo pre-transplant through 36th mo if transplant occurs within 2 mo,	N/A
Employer group	From 31st – 36th mo	From 1st – 30th mo
Anyone whose transplant rejects who starts dialysis		
No employer group	From 1st of mo dialysis as long as dialysis continues	N/A
Employer group	From 31st mo on	From 1st – 30th mo
New employee with employer health coverage		
In-center dialysis	From 33rd mo on	To 33rd mo
Home/self-care dialysis	From 31st mo on	To 31st mo
Transplant / not disabled	From 31st mo – 36th mo	To 31st mo
Transplant / disabled	From 31st mo on	To 31st mo

What Medicare Covers For Dialysis and Transplantation

Dialysis

Service/Supply	Medicare Part A (Hospital)	Medicare Part B (Medical)
Inpatient services	✓	
Outpatient dialysis		✓
Home/self-care training		✓
Home dialysis equipment & supplies		✓
Certain home support services		✓
Some drugs needed for home dialysis		✓
Epogen (epoietin alfa)		✓
MD services		✓
Services: Labs, x-ray, etc.		✓
Ambulance transportation		✓

Not covered: home dialysis helper, lost pay, lodging for training or treatment, non-emergency transportation

Transplant

Service/Supply	Medicare Part A (Hospital)	Medicare Part B (Medical)
Inpatient service	✓	
Kidney registration fee	✓	
Recipient's lab testing	✓	
Donor's lab testing	✓	
Locating cadaveric donor kidney	✓	
Cost of kidney donor's care	✓	
MD services for recipient		✓
MD services for donor		✓
Immunosuppressives Disabled or aged: indefinite Not disabled: 1st to 36 mo		✓

Dialysis or Transplant

Blood, >1st 3 pts	✓ if inpatient	✓ if outpatient
Physical therapy*		✓
Occupational therapy*		✓

**Someone with kidney failure must have a covered diagnosis; kidney failure alone will not warrant coverage. Rehabilitation professionals know covered diagnoses and services.*

Source: Medicare Coverage of Kidney Dialysis and Kidney Transplant Services (HCFA 10128)

Rehabilitation Timeline For Dialysis Professionals

A Sample Renal Rehabilitation Timeline

Focusing rehabilitation efforts early in dialysis yields better outcomes.

Diagnosis	Modality selection	First 90 days of dialysis	Six months after dialysis begins	One year after dialysis begins
• Education on fitness; treatment options; maintaining employment; insurance and benefits; adjusting to life with dialysis with positive expectations* • Psychological support	• Family orientation to dialysis • Education about self-care, patient rights and responsibilities, access care, diet, exercise, other life activities* • Employer education, if necessary • Vocational Rehabilitation (VR) assistance in evaluating and modifying workplace, if necessary • Peer group support	• Diagnostic assessment to determine necessary rehabilitation interventions • Rehabilitation goals incorporated into treatment plan after diagnostic assessment • Functional status assessment* • Education re adequacy, patient rights and responsibilities, self-care, legal rights in employment • Referral for physical therapy, occupational therapy, community-based exercise program, if appropriate • Employer education and workplace accommodation, if needed • On-going peer group support	• Encourage functional rehabilitation and exercise* • Review rehabilitation goals and revise if necessary* • VR follow-up* • On-going peer group support* • On-going education*	• Encourage functional rehabilitation and exercise* • Review rehabilitation goals and revise if necessary* • VR follow-up* • On-going peer group support* • On-going education*

decreasing function ***stabilization*** ***adaptation***

* Represents activity that should be either on-going or repeated periodically throughout the course of the patient's total dialysis program

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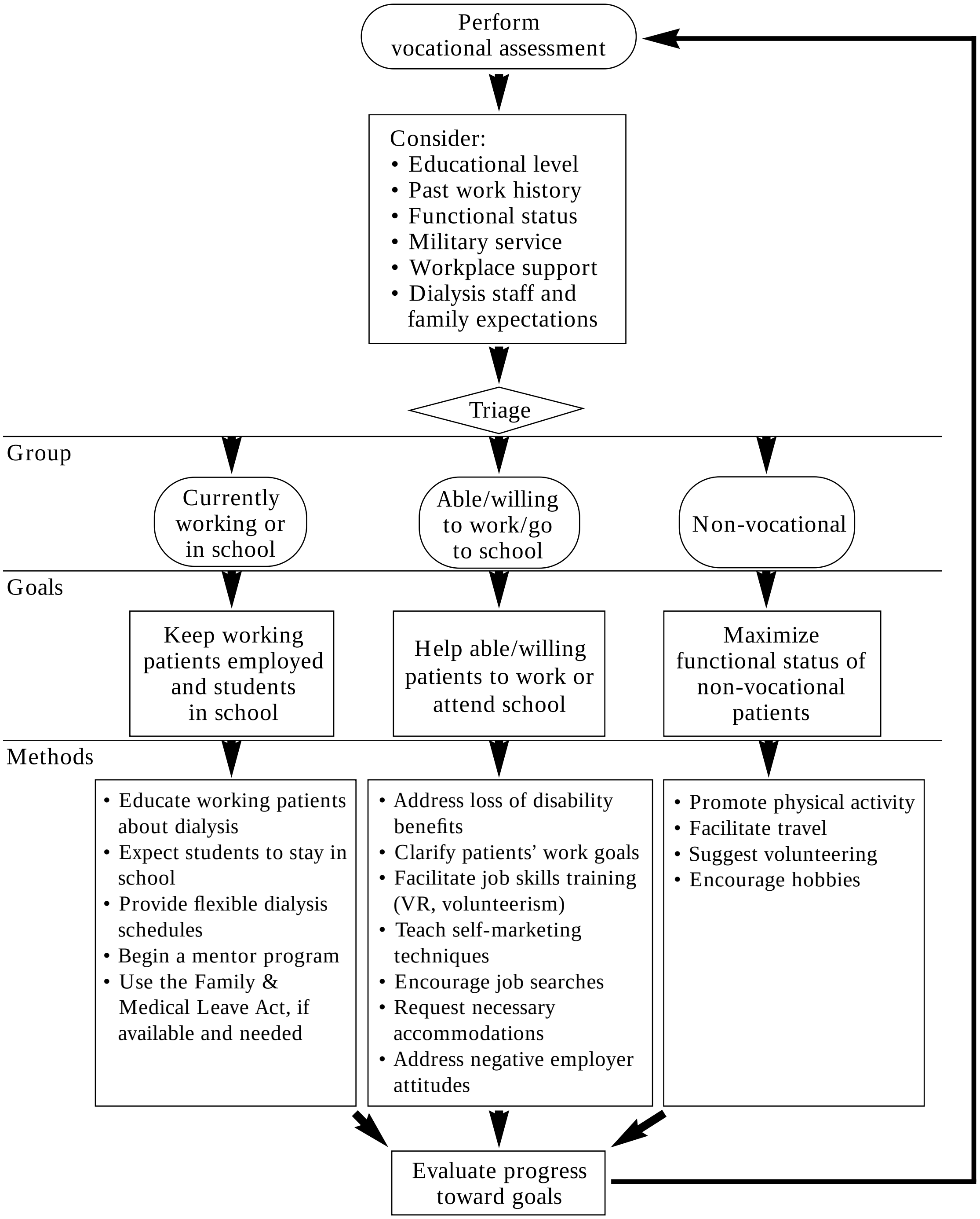
Rehabilitation Flow Chart For Dialysis Professionals

Renal Rehabilitation: Employment at a Glance



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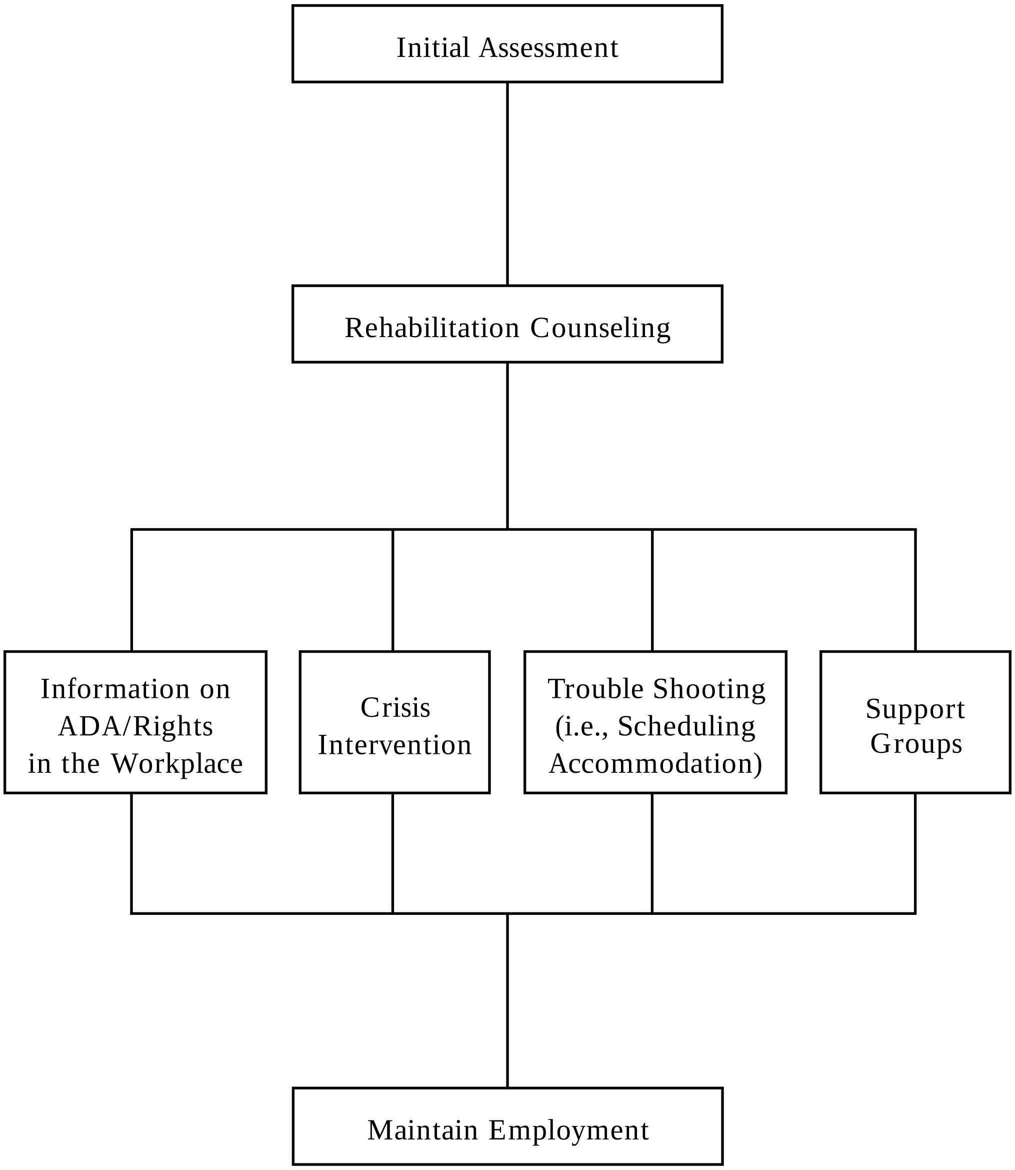
Flow Chart: Currently Working Clients



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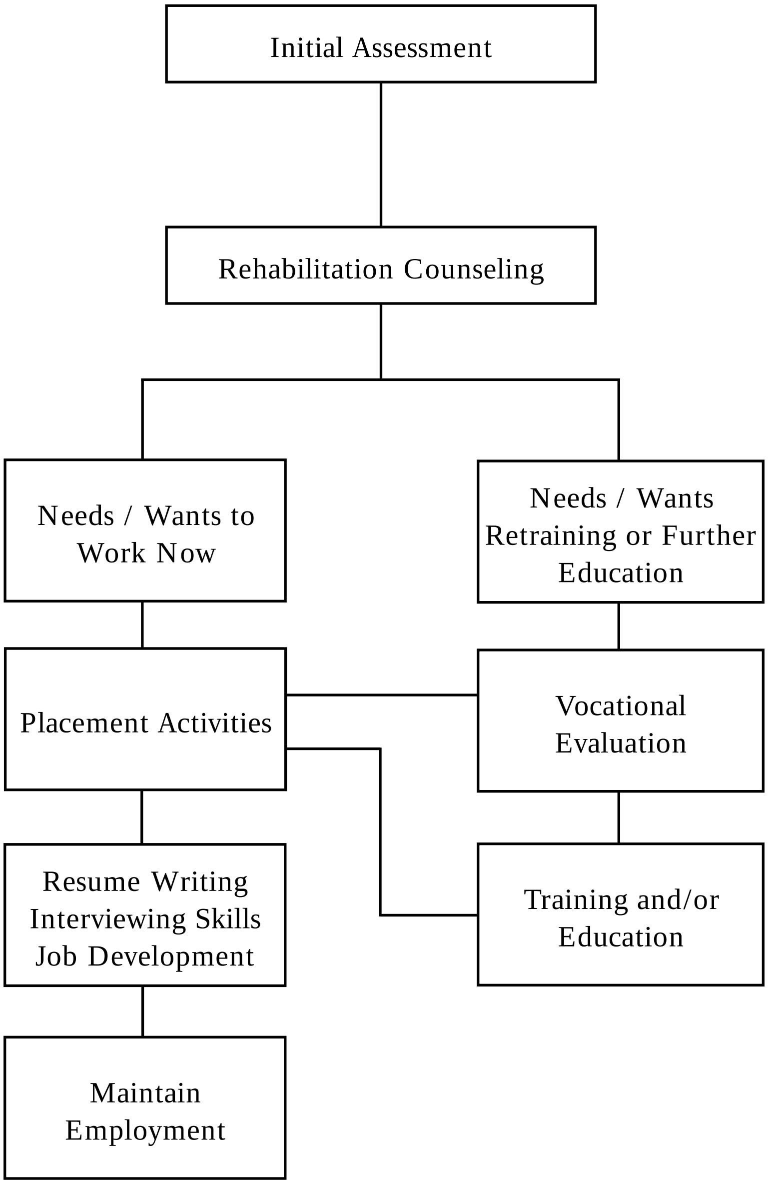
Flow Chart: Non-Working Clients With Recent Work Histories Or Transferable Skills



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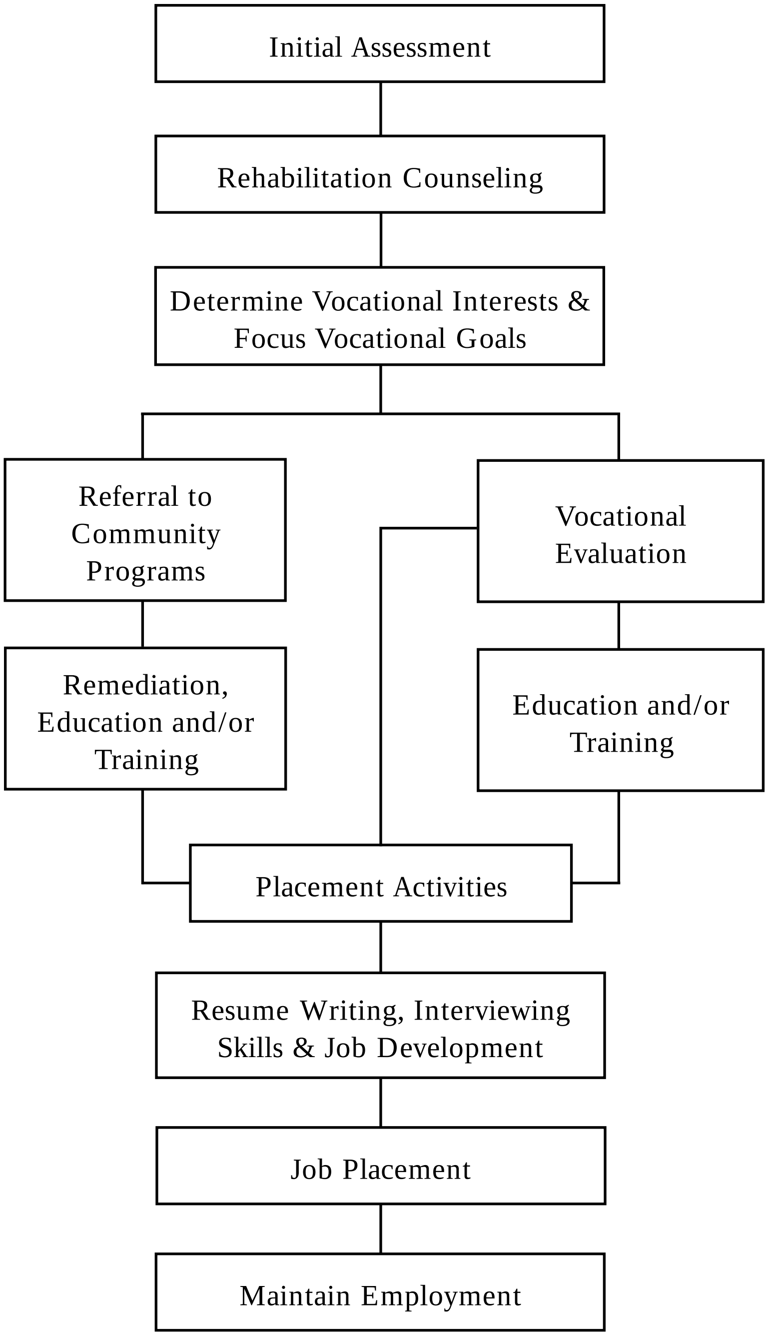
Flow Chart: Non-Working Clients Who Need More Structured And Supportive Rehabilitation Planning



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What is RISE?

RISE (Rehabilitation, Information, Support and Empowerment) is a comprehensive approach to motivating individuals with kidney disease to return to meaningful activity, which may involve resuming daily routines, employment, continuing education and/or volunteering. The program offers kidney patients a chance to assess their skills, values and interests in relation to their quality of life and career goals. Topics discussed include resume writing, interviewing skills, rights and responsibilities of individuals with kidney disease, rehabilitation services, and insurance. RISE recognizes that patients may need to develop the essential tools to help them become more independent.

A Total Program

RISE consists of four comprehensive, full-day classes:

Day 1 - Taking Charge

Day 2 - Rights and Responsibilities

Day 3 - Making Your Skills Work For You

Day 4 - Developing a Plan

A Collaborative Effort

RISE draws on the knowledge, skills and expertise of caring professionals and the experience of people with kidney disease. The RISE program involves a collaborative effort of a specially trained Program Coordinator and two specially trained Program co-moderators. The Program Coordinator is an employee of the organization providing the program. One Program co-moderator is an individual with kidney disease; the other is a professional who has knowledge of rehabilitation such as a renal health care professional or a vocational rehabilitation counselor. These individuals work closely with the extensive faculty team and patient presenters to ensure that the objectives and high standards of the program are met.

The faculty, who provide professional expertise for the program, include renal social workers, renal dietitians, exercise facilitators, and representatives from the following organizations and agencies available in the area:

- ESRD Network
- State Vocational Rehabilitation Services

- Social Security Administration
- Equal Employment Opportunity Commission
- Temporary Employment Services
- Human Resources Consulting Firm
- College Placement Office and Center for Independent Living

People receiving treatment for kidney disease participate as patient presenters, sharing their experiences related to returning to school, work or volunteering. These individuals serve as positive role models with whom the participants can identify. For more information on RISE, call the National Kidney Foundation at (800) 622-9010.

What is People Like Us, Live!?

"People Like Us, Live!™" is an interactive patient education program which openly addresses the many fears and concerns that patients and family members face when diagnosed with chronic renal failure, and provides the objective, unbiased factual information they need in order to make informed treatment and lifestyle choices. It encourages these individuals to take an active part in making decisions that will affect their overall quality of life and gives them hope.

A Total Program

People Like Us, Live!™ consists of the following six 1 hour classroom presentations:

Introduction to Kidney Disease and its Treatment
Hemodialysis - Choosing a Treatment That's Right For You
Peritoneal Dialysis - Choosing a Treatment That's Right For You
Transplantation - Choosing a Treatment That's Right For You
Good Nutrition - Eating Right To Stay Healthy
Coping and Other Lifestyle Issues - Managing Your Kidney Disease

A Collaborative Effort

People Like Us, Live!™ draws on the knowledge, skills and experience of caring health care professionals and patient presenters who recognize the importance of the program's goals and want to play an important role in achieving them. An MSW nephrology social worker with a minimum of one year of renal experience serves as Program Moderator and works in partnership with an NKF Affiliate staff member who serves as Program Coordinator. Both are trained and certified by the National Kidney Foundation to jointly conduct the program. The program is designed to be conducted through the local NKF affiliates.

Faculty for each class is drawn from the local renal health care community and includes renal nurses experienced in home and in-center hemodialysis and the different forms of peritoneal dialysis, renal dietitians, renal transplant nurses/clinical coordinators and renal social workers.

Patient presenters are people on treatment and their families who also participate as members of the faculty by sharing their unique experiences and perspectives with diagnosis, treatment selection and coping strategies.

For more information about People Like Us, Live!, call the National Kidney Foundation at (800) 622-9010.

Club Independence (Georgia only)

Club Independence is a three-day vacation retreat for adults debilitated with kidney disease to re-energize and renew their independence. These retreats are a time for fun and freedom. Activities include sports, recreation and leisure activities as well as a full range of educational classes about kidney disease. There is only a nominal administration/transportation fee.

Who is eligible to attend?

All kidney patients must meet specific requirements concerning compliance with medication and dialysis visits. These rules have been established to ensure that the reward of this vacation weekend is only available to patients who are taking good medical care of themselves. There are no exceptions.

Eligibility Criteria for Club Independence

1. **Compliance with Treatment**
    - No skipping treatment or dialysis
    - Faithfully following orders given by the doctor
    - Good glucose control
    - Good blood pressure control

2. **Controlling Fluid Restrictions Between Treatments**
    - Keeping fluid gains to a minimum

3. **NO Abuse of Alcohol or Illegal Drugs**
    - No current history of alcohol or illegal drug abuse

4. **Compliance with Diet**
    - Lab work has to be within normal limits

5. **Good Attitude at Dialysis Clinic and/or While Dialyzing**

6. **NO Signing Off Early at Treatment**

7. **Signature from a Social Worker or a Nurse Saying that the Patient has been Compliant with the Above Guidelines.**

For more information, please see the social worker at your dialysis clinic or call (770) 452-1539, ext. 11 or outside the Atlanta metro area at (800) 633-2339.

Springboard (Georgia only)

What is Springboard?

- A program for young adults 19-30 years old with kidney disease or kidney transplants.
- Four wonderful, free weekends away from home at different locations across Georgia (held between November and May – on an every other month schedule).
- A chance to meet other people just like you – other young adults with kidney disease, facing the same issues as you.
- A program to help you grow and learn about all of the opportunities that are available for you.
- A place where you can be yourself!

Who is eligible to attend?

In order to be a part of this fun & exciting program you must be:

- between the ages of 19 & 30
- a kidney patient on dialysis, waiting for a kidney transplant or have already had a transplant
- able to have fun & enjoy yourself

Applicants to the program form a “team of participants” who together with NKFG volunteers & staff, will travel to all four (4) weekends of the program. Each weekend is full of exciting things – which is why being at each weekend is so important. If a participant misses the first weekend, they will be asked to wait until the following year to begin the program.

How can I learn more?

Think you or someone you know might be interested in Springboard? To learn more about Springboard, call (770) 452-1539, ext. 20.

A Report Of The Surgeon General: Physical Activity And Health For Persons With Disabilities

Key Messages

- Physical activity need not be strenuous to achieve health benefits.
- Significant health benefits can be obtained with a moderate amount of physical activity, preferably daily. The same moderate amount of activity can be obtained in longer sessions of moderately intense activities (such as 30-40 minutes of wheeling oneself in a wheelchair) or in shorter sessions of more strenuous activities (such as 20 minutes of wheelchair basketball).
- Additional health benefits can be gained through greater amounts of physical activity. People who can maintain a regular routine of physical activity that is of longer duration or of greater intensity are likely to derive greater benefit.
- Previously sedentary people who begin physical activity programs should start with short intervals of physical activity (5-10 minutes) and gradually build up to the desired level of activity.
- People with disabilities should first consult a physician before beginning a program of physical activity to which they are unaccustomed.
- The emphasis on moderate amounts of physical activity makes it possible to vary activities to meet individual needs, preferences, and life circumstances.

Facts

- People with disabilities are less likely to engage in regular moderate physical activity than people without disabilities, yet they have similar needs to promote their health and prevent unnecessary disease.
- Social support from family and friends has been consistently and positively related to regular physical activity.

Benefits of Physical Activity

- Reduces the risk of dying from coronary heart disease and of developing high blood pressure, colon cancer, and diabetes.
- Can help people with chronic, disabling conditions improve their stamina and muscle strength.
- Reduces symptoms of anxiety and depression, improves mood, and

promotes general feelings of well-being.
- Helps control joint swelling and pain associated with arthritis.
- Can help reduce blood pressure in some people with hypertension.

What Communities Can Do

- Provide community-based programs to meet the needs of persons with disabilities.
- Ensure that environments and facilities conducive to being physically active are available and accessible to people with disabilities, such as offering safe, accessible, and attractive trails for bicycling, walking, and wheelchair activities.
- Ensure that people with disabilities are involved at all stages of planning and implementing community physical activity programs.
- Provide quality, preferably daily, K-12 accessible physical education classes for children and youths with disabilities.
- Encourage health care providers to talk routinely to their patients with disabilities about incorporating physical activity into their lives.

For More Information Contact:

Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion
Division of Nutrition and Physical Activity, MS K-46
4770 Buford Highway, NE
Atlanta, Georgia 30341-3724
(888) CDC-4NRG or (888) 232-4674 (Toll Free)
www.cdc.gov

The President’s Council on Physical Fitness and Sports
Box SG
Suite 250
701 Pennsylvania Avenue, NW
Washington, DC 20004
www.fitness.gov